

PositiveLiving

a magazine for people living with hiv/aids february-march 2005



SUPER BUG or a storm in a teacup?

BY PAUL KIDD

In a story that generated massive worldwide media interest, public health authorities in New York announced on 11 February that they had detected a single case of an apparent "new strain" of HIV which could lead to AIDS in months, not years, and was resistant to virtually all antiretroviral drugs.

The patient at the centre of the story, a gay New York man in his 40s who was first diagnosed with HIV in December, was said to have frequently engaged in unprotected sex, often while also using methamphetamine (crystal meth).

Calling the case a "wake-up call to men who have sex with men, particularly those who may use crystal methamphetamine," the city's health commissioner, Dr Thomas Frieden, described the

man's condition as "difficult or impossible to treat."

The announcement led to the issue of a national alert by the Centres for Disease Control (CDC) and, within hours pundits, commentators and experts across the US and around the world were weighing in with their assessment of the significance – or insignificance – of the case.

While the official announcement and much of the media response to the case was sensational, at least some clinical experts urged caution. Dr Robert Gallo, one of the co-discoverers of HIV, said he thought the story was "much ado about nothing."

Thomas Jefferson University specialist Dr Roger Pomerantz went further: "Every medical centre in a major metropolitan area will have a case like this," he said. "You've got to really prove

something before you go on CNN and scream about a super-strain."

Dr Andrew Grulich of the National Centre in HIV Epidemiology and Clinical Research told *PL* that he believes the response of the US authorities was somewhat alarmist given that only a single case had been identified. "The way it emerged appeared to be pretty much like 'science by press release'," he said.

Grulich doubts the case represents a new strain of HIV, as has been widely claimed. "I don't think based on a single case you can make any conclusions about a new strain of HIV," he said.

The natural course of HIV can be "extraordinarily variable," Grulich explained – numerous cases of people progressing from infection to AIDS within a year or less have occurred, although not before with such

a highly drug-resistant virus.

"We've certainly seen cases in Australia where people have progressed rapidly from HIV infection to AIDS within a year – we would have seen many cases of that over the last 20 years – but it's not a common occurrence," he said. Likewise, there have been many cases of people having multi-drug resistant virus, but it is unusual that the two should occur in the same individual.

In the days following the New York announcement, Canadian HIV physician Dr Julio Montagner pointed out that several similar cases had been detected in Vancouver in 2001 and were described in the medical literature, but had not proven to be a new strain of HIV.

Grulich cautions that further evidence would be needed to support the idea that a new strain was emerging. "If

we saw a cluster of ten or 20 of these cases in New York – or in Sydney – then there absolutely would be something to worry about but there's no evidence that will be the case or has been the case," he said.

He is also troubled by the way the impact of the man's drug use has been represented. "Some of the press implied that crystal meth might have caused this organism to be resistant or caused it to be rapidly progressive, and that's pure and simple nonsense," he said. There is evidence that crystal meth and other recreational drugs are linked to unsafe sex, he noted, but said media reports linking them to resistant HIV were unhelpful.

Michael Hurley, a senior research fellow at the Australian Research Centre in Sex, Health and Society, says the media's handling of the story is an example (to page 2)

INSIDE

Hep C coinfection
latest research ■ treatments ■ sexual transmission

Bucket collection blues

A flood of protests to the Sydney Gay and Lesbian Mardi Gras led to an eleventh-hour reversal of a controversial decision to halt PLWHA (NSW)'s annual cash collection at the organisation's festival launch. The bucket collection, which has for ten years been PLWHA (NSW)'s major fundraiser, was allowed to go ahead, but Mardi Gras organisers say this will be the last year the bucket collection will benefit people with HIV/AIDS.

Women at the forefront

Positive women are "resilient and resourceful leaders and catalysts of action," the United Nations AIDS program said in a statement to mark International Women's Day on 8 March. As well as making up the majority of the world's people living with HIV/AIDS, women provide love and care to affected family members, often with minimal support, the statement said. Last year the UN launched the Global Coalition on Women and AIDS, bringing together activists, NGOs, networks of women living with HIV, governments and UN agencies.

HIV 'stalemate'

Medical science is locked in a 'stalemate' in the fight against HIV/AIDS, according to one of the co-discoverers of HIV, Dr Robert Gallo. While antiretrovirals have been a 'godsend' for HIV-positive people who can afford them, the progress of the epidemic remains unpredictable in the developed world, continues to devastate Africa and is on the rise in Asia and Eastern Europe. "It will be a problem for our children and our children's children unless we can solve it through potent education and getting the drugs out there," he said.

African PrEP trial halted

A clinical trial investigating the use of tenofovir for HIV prevention in Cameroon has been halted by the country's health ministry after protests by ACT-UP Paris, which claims the trial is "counter to ethical norms." The US-funded trial, in which HIV-negative commercial sex workers were to be given tenofovir in the hope that it can prevent HIV infection, is also running in Ghana, Nigeria and Malawi, however a proposed Cambodian arm was also halted last year on the orders of the Cambodian prime minister. The trial organisers say they will address the Cameroonian government's concerns and are hopeful that the study will continue.

No more infant AIDS?

Public health officials in the US say that mother-to-child transmission of HIV has almost been eliminated in that country. In what they described as "a dramatic and wonderful success story," officials said the number of babies born with HIV infection had dropped from a high of around 2000 per year in 1999 to around 200. The fall is due to improved antiretroviral therapy as well as increases in the number of pregnant women who know their HIV status before giving birth.

Condoms the key

Programs promoting abstinence and monogamy in Uganda are failing, and the country's success in fighting AIDS is more due to condom use than anything else, according to a report presented to the Retrovirus conference in Boston. The extensive study found very high levels of condom use in Uganda, contradicting claims that abstinence and faithfulness were the basis of Uganda's success in combating HIV.

TEddI study recruiting

BY TONY MAYNARD

Adherence problems have long been identified as a major cause of failure of treatments for HIV infection. Newer, simpler combinations of HIV drugs are hoped to make it easier for positive people to take their medication regularly.

There remains some uncertainty about the importance of once-daily, versus twice-daily, dosing of medication in the treatment of HIV infection as well as in other medical conditions. However there is a gradual shift towards once-daily dosing. While this is happening it would seem worthwhile to investigate this trend. Once-a-day dosing may be more or less important than we think.

'TEddI' is the first randomised multi-centre study looking at the importance of compliance in the success of HIV treatment in Australia. Participants in 'TEddI' are randomised to either continue their current twice-daily medications or switch to a once-daily combination. Any combination of once-daily medications is allowed.

After 24 weeks, all patients will switch to the once-daily combination. The study lasts for 12 months in total.

Four different methods



are being used to measure adherence with medication – electronically monitored pill bottles ('MEMS caps'), questionnaires, provider estimates and therapeutic drug monitoring blood tests. The efficacy of the different adherence measures will be compared during analysis of the results.

These are worthwhile questions to answer. There is evidence that people adhere better to regimens when fewer pills need to be taken less often – as was seen in the Zodiac study which compared abacavir and 3TC taken once or twice daily.

But there has been little attention to adherence studies here in Australia. The hope with TEddI is that clinicians will gain greater understanding of the factors contributing to adherence in

Australian patients. This can only be a good thing.

As a bonus, participants in the study will have their medication costs covered while participating in a study increasing experience and focus on adherence in medical care.

The study was first conceived over three years ago, and originally was designed to use three drugs (tenofovir, efavirenz and ddI), thus the name TEddI. This combination has since been found to have unacceptably high rates

of failure, and has been dropped from the study, which was then extended to allow the use of any licensed once-daily medications.

There are now six antiretroviral drugs licensed in Australia for once-daily dosing: didanosine (ddI), lamivudine (3TC) efavirenz, tenofovir, atazanavir and abacavir. A seventh, FTC, will be available shortly.

TEddI is a community-initiated and pharmaceutical industry sponsored trial, and is aiming to recruit 200 participants. Recruitment is progressing steadily however more volunteers are needed. Ten clinics in Melbourne and Sydney are participating in the study.

■ For further information about this study, contact your GP.

SUPER BUG

from page 1

of the way in which sex, drugs and HIV are represented by the media as scandal.

"It's a ready-made news story akin to 'sex, drugs and rock and roll'," he said.

"Culturally, gay men are 'other' in the sense that their perceived sexual excesses are both envied and anxiety-provoking," Hurley said. "The price of this is that they can be easily represented as out of control and shockingly dirty."

"None of this is to deny New York City has a major HIV epidemic that sits on the edge of being out of control. That's the real issue, the real scandal, but in a country that cannot deal politically or officially with sexual and other life realities it's very difficult to do sensible public health," he said.

Grulich believes the case should remind us that HIV remains a serious disease. "This unfortunate person developed AIDS within a year with a multiply drug-resistant organism that's going to be very difficult to treat," he said. "Some people who are being infected with HIV even today are unlucky enough to have very difficult to treat disease, so it does highlight that HIV is still a serious disease and in some cases is close to untreatable still."

But he does not believe that generating fear is helpful: "We have a very sophisticated gay community and HIV-positive community," he said, "and if it sees bad science and inappropriate use of fear it'll see straight through it – that can have a counter-productive effect of leading to a lack of trust of health authorities such as the one that released these results."

Our Place, Your Place...

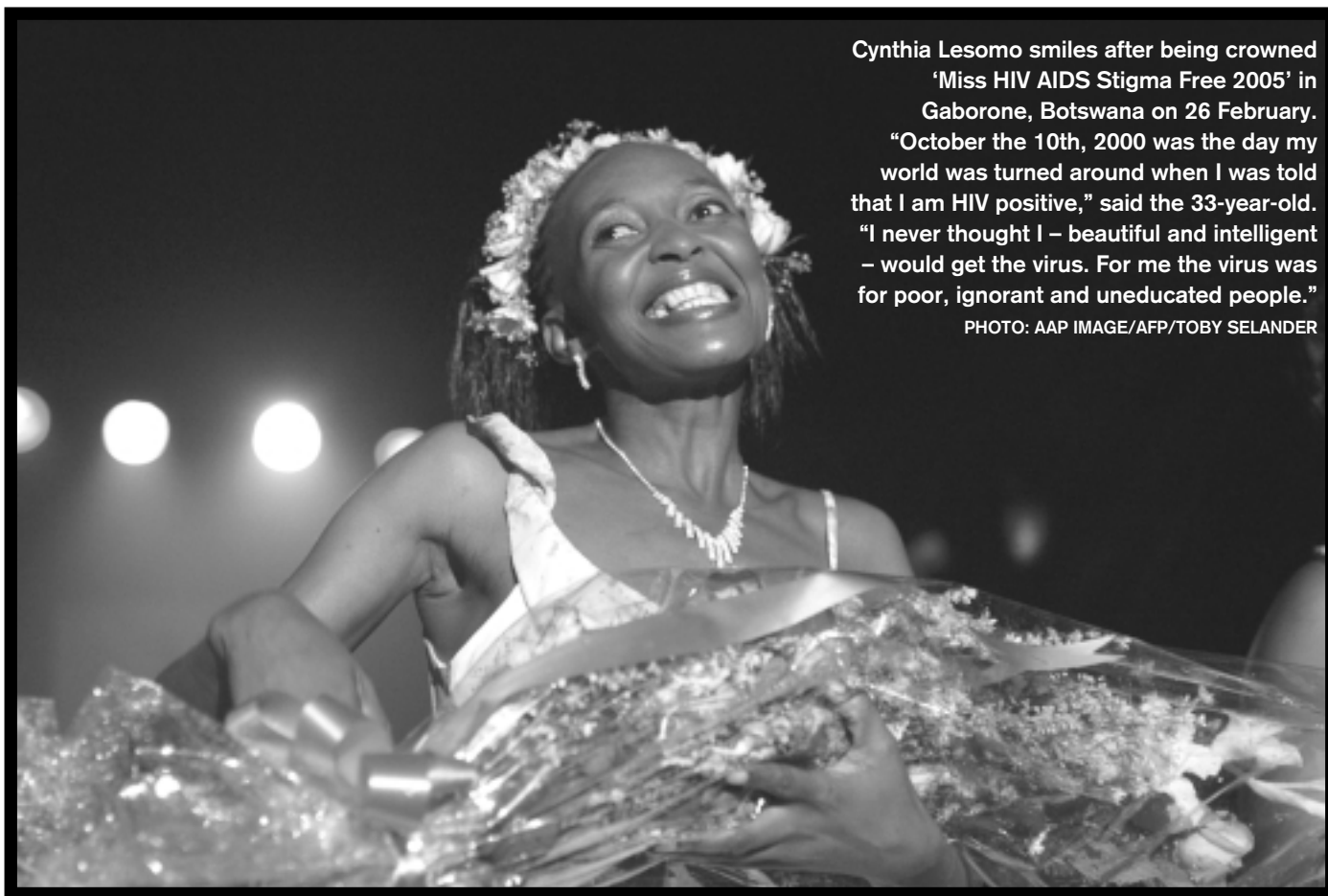
...in the bigger picture

**Tenth National Conference
of People Living with HIV/AIDS**
Adelaide, South Australia • 18–20 November 2005

napwa

NATIONAL ASSOCIATION OF PEOPLE LIVING WITH HIV/AIDS

National Association of People Living with HIV/AIDS
Conference 2005 Secretariat, LMB 5057 Darlinghurst NSW 1300
(02) 9368 2718 • conferenceinfo@napwa.org.au • www.napwa.org.au



Cynthia Lesomo smiles after being crowned 'Miss HIV AIDS Stigma Free 2005' in Gaborone, Botswana on 26 February. "October the 10th, 2000 was the day my world was turned around when I was told that I am HIV positive," said the 33-year-old. "I never thought I – beautiful and intelligent – would get the virus. For me the virus was for poor, ignorant and uneducated people." PHOTO: AAP IMAGE/AFP/TOBY SELANDER

THIS *issue*

HIV in its place	David Menadue asks how positive people today make room in their lives for HIV?	4
Hep cats	Special report on hepatitis C coinfection, treatment, care and transmission	5
In the pipeline	Kirsty Machon looks at some new and promising anti-HIV drug developments	7
Near neighbours	Australian people living with HIV/AIDS are reaching out to Papua New Guinea	8
Positive Voices	Coming to terms with side effects takes time, but it's worth it, writes Sam Pesci	9
REGULARS		
Complementary therapies		6
Treatment briefs		6
Backgrounders		11
PLWHA Broadsheet		12

Verbatim

"Giving up sex to avoid HIV is like cutting off your foot so you don't get an ingrown toenail – there are much more effective ways of avoiding what you don't want."

Victorian AIDS Council executive director Mike Kennedy, responding to speculation that the Fifth National HIV/AIDS strategy would include measures promoting abstinence, in the Melbourne *Star*.

"Children have lost their parents because of AIDS, and old people have lost their sons and daughters. It has destroyed many families. But with the loving care of the Communist Party and the government, we have again established a sunny home."

Chinese premier Wen Jiabao, shown shaking hands with HIV-positive people on Chinese television during festivities to mark the Lunar New Year in early February. Mr Wen spent the New Year in Henan province, where many people contracted HIV via unsafe blood collection procedures in the 1990s.

FIGURE *this*

2 million

The number of years of life saved to date by HIV treatment in the United States, according to a study that for the first time quantified the total impact of HIV treatment in the US.

10

The percentage of Europeans with a genetic mutation that makes them partially immune to HIV infection. Biologists from the University of Liverpool have discovered the mutation can be traced back to the plague epidemics of the middle ages.

39.4 million

The number of people living with HIV/AIDS worldwide at the end of 2004, according to the latest report from UNAIDS. New infections in 2004 were estimated at 4.9 million, and 3.1 million people died of AIDS-related causes.

ACTIONALERT

Private Lives: is an ambitious national survey – the biggest of its kind ever conducted in Australia – looking into the health and wellbeing of gay, lesbian, bisexual and transgender people, both HIV negative and positive. Conducted by Gay and Lesbian Health Victoria in partnership with the Australian Research Centre in Sex, Health and Society at La Trobe University (which also conducts the HIV Futures studies), the study looks at a wide range of health-related issues and promises to be a vital tool for health service planning. The anonymous, confidential survey can be completed online at www.privatelivessurvey.com.au.

'Work-for-the-pension' plan mooted

BY PAUL KIDD

With HIV advocates still anxiously awaiting the federal government's announcement of plans to restructure the Disability Support Pension (DSP), on 4 March the Human Rights and Equal Opportunity Commission announced a national inquiry into employment for people with disabilities.

The government's plans are not yet known, but they are widely anticipated to include a considerable tightening in the eligibility criteria for the pension. At present, people who are assessed as unable to work more than 30 hours per week are able to access the DSP. The government has previously attempted to reduce this to 15 hours, but the changes failed to attract Senate support.

With the government set to control both houses of Parliament from 1 July, those changes are expected to be reintroduced, along with a package of other measures which could extend the philosophy of 'mutual obligation' into disability pensions for the first time.

The changes are widely tipped to include provisions similar to the 'work for the dole' scheme whereby DSP recipients who are assessed as capable of working more than the 15-

hour threshold may be penalised if they do not take up employment.

"Ultimately, if we get to a stage where somebody basically says, 'although I am capable of working I don't want to work,' well we'll have to look at what the consequences of that are," the employment minister, Kevin Andrews, told ABC Radio on 28 February.

NAPWA Care and Support Convenor Rob Lake told *PL* that HIV-positive DSP recipients are naturally worried about what the changes might mean for them.

"I think people are concerned that if they leave the pension, they might not be able to stay in a job, and they'll end up on Newstart," he said. "That's limiting people's ability to make choices, to try that, and it's limiting our ability to encourage them to give it a go."

There are suggestions that the new rules may apply only to new applicants for the DSP, and that the current provisions may stay in place for existing recipients, however the government has not confirmed this.

The HREOC inquiry, which will publish its findings in November, will examine the barriers to people with disabilities seeking employment, and issues for employers in recruiting or

retaining employees with disabilities.

Lake said the government should implement a more comprehensive consultation process and delay making any final decision on plans to change the DSP until the HREOC inquiry is completed.

Appropriate compensating measures also need to be implemented as part of any reform package if eligibility is tightened: changes to the way earned income is assessed and taxed and entitlement to health care concession cards are two areas Lake said the government should consider.

"The Health Care Card is a really significant and valuable federal concession," said Lake, who argues that health care concession benefits should be extended to working low-income earners with chronic illnesses such as HIV/AIDS.

NAPWA will be making a submission to the HREOC inquiry and consulting with the government on the proposed changes.

■ **Adult pension and allowance rates will increase from 20 March. The maximum single rate pension will rise by \$5.60 per fortnight, or 1.2 percent, to \$476.30 per fortnight, in line with inflation.**

Eureka! Aussie OPAL shines

Researchers at the University of Melbourne say they have made a chance discovery that could lead to treatments to drastically boost the body's natural immune response to HIV and other viruses.

The breakthrough, reported in the *Journal of Virology*, involves using a patient's own blood treated with small overlapping HIV

proteins called peptides.

The team was working on a technique to measure the effectiveness of HIV vaccines when they made a serendipitous discovery.

After extracting blood from vaccinated laboratory animals, they coated the cells with peptides – marker chemicals that show the immune system when a cell is infected by a virus. When

they reinfused the animals with the treated blood, it triggered an immune response against HIV.

"The technique was also effective for boosting the immune response to Hepatitis C peptides and we believe that it could be refined for many different viral infections and cancers," said Associate Professor Stephen Kent.

"We have also shown it can be used to induce immune responses against drug resistant forms of HIV."

The researchers call the procedure Overlapping Peptide Pulsed Autologous Cells (OPAL). They have been awarded a half-million-dollar grant to further develop the technique so that it can be studied in humans.

Sometimes I feel like a bit of an 'HIV tragic'. I have been involved in HIV organisations and committees related to HIV

for more than ten years, over half of my friends are HIV-positive and I spend a good part of every week thinking about the subject in some way or other. I've even written for every issue of *Positive Living* since it became national in 1995.

So I thought it would be interesting to talk to a range of other positive people who I think are a little less attached to the sector than me and who have survived for a long time with HIV, to find out how they have assimilated HIV into their everyday lives, how they cope with issues like treatments and side effects and if they still feel the uncertainty – even fear – that used to be an issue for lots of positive people pre-HAART. Have things changed that much?

TWENTY-ONE YEARS BUT NO CELEBRATION

James* has had a successful career in finance and, heading towards his mid-fifties, is looking forward to early retirement. He has been with his partner for twenty years and while the relationship is platonic these days, it provides James with a crucial support around the big issues in his life, which, at least twenty-one years after being diagnosed with HIV, are still largely to do with the virus.

On the surface and on most markers in life James has achieved a lot and is relatively content – his health is excellent, and he swims and attends aerobics classes several times a week – but it seems HIV continues to prove a challenge in his everyday life, a negative he could really do without.

"I think about it every day," he said. "It's hard not to when you're shoving pills down your throat three times a day."

James's T-cells started to drop in 1996 from a regular 600 mark to 187 and his doctor, who he has been seeing since the mid-eighties, suggested it was time to start treatments. "The treatments have been the only difficulty I've had when it comes to the physical problems of living with HIV: the virus has not done anything to make me ill," he said.

James had enormous respect for his doctor but it was a difficult decision to start treatments because he had survived for so long without them, despite losing numerous friends, and a former lover, along the way.

His health just continued to keep on regardless. "I'm still surprised that no researcher has ever asked to look at people like me who have survived for so long with no AIDS illnesses at all. Because I'd made it so far, I found it



The place of HIV in your life

hard to admit I needed some assistance. I met another positive guy who had survived a long time too and he was doing it with Chinese herbs and acupuncture and I felt a bit of an idiot. Had I jumped onto the Western medicines bandwagon as soon as there was a sign of trouble?"

Adjusting to an AZT/3TC/indinavir regimen did take some patience as he soon found he experienced flatulence (instantly, as soon as he took an indinavir capsule), diarrhoea, bad breath and a loss of libido. But he persevered for eight years as his markers went back to normal and he had an undetectable virus again. Last year though he was hospitalised with kidney stones (a known side effect of indinavir) and moved over to nevirapine to replace the offending protease.

"It was a painful experience but now I'm back where I was clinically, I'm feeling invincible again."

Except when it comes to sex. James's big issue, one he has carried around with him for the whole time he has had the virus, has been transmission and the fear that sexual partners will reject him because of his status.

"I had the worst thing happen at a sauna about five years ago. A guy was starting

to give me oral sex and I stopped him saying, 'Look you need to know before you do that that I'm HIV-positive.' His reaction was extreme, saying, 'How could you do this to me? I'm going to report you to the sauna management. People like you shouldn't be allowed in here.'

"It was so uncomfortable my mind just snapped. I decided I couldn't keep putting up with that tension every time I was about to have sex. I just decided to be celibate and I've remained that way for the past five years. It's been liberating in a kind of way. I also feel uncomfortable about kissing some casual friends and I also tend not to mention that I'm positive to all but my closest friends, these days.

"I'm coping all right with everything but I'm not so relaxed about the future, really. I'm not certain about my prognosis and think I will be more likely to come down with some nasty kidney or pancreatic cancer related to my treatments, than directly to HIV," he said.

"But then again of course, I might die from old age."

THE NEED FOR BALANCE

Joe is very different although he has a similar history with the virus to James. He was diagnosed with HIV in 1987 but has probably had it since

the early eighties when he was with an American lover who turned out to be positive as well when the test became available in 1984.

He had excellent health until 2003 when his T-cells started to show a pattern of decline and he started treatments. He said he has absolutely no regrets about the decision to start treating, but it was taken after talking to lots of friends with HIV about the likely side effects he might experience.

"I decided that taking treatments was a positive step towards improving my health. Instead of regarding the drugs as poison, I expected them to work for me," Joe said. But his patience was tried by his first combination, based on efavirenz which gave him a "fuzzy head" and caused insomnia.

"Even after about eight months I was groggy in the mornings although I've now learnt to live with it and my clinical results have been good."

Like James, Joe thinks having a long-term partner (for 14 years) has been an essential part of why he has done so well. His partner is HIV-negative, something he thinks is a blessing.

"I know some pos guys think it might be stressful having a neg partner but for

me it is less stress not having to worry about my partner's health as well. We have practiced safe sex from day one – it is just the way it is for us sexually and neither of us really wants that to change. We don't have any fear of transmission. Occasionally I have had unprotected sex with other positive guys which I don't think is risky as I have regular check-ups for STIs and know that, if superinfection is a reality, I have no resistant virus that I can pass on to them"

On the issue of the place of HIV in his life, Joe thinks it is important to find a balance with the activities you do and the people you mix with regularly.

"I used to work in the HIV sector and was surrounded by HIV issues and lots of other positive people every day. Having a negative partner helped but I also deliberately formed relationships with straight and gay people who had absolutely nothing to do with that part of my life. I'm happy to attend events at PLWHA Victoria or the AIDS Council but I have been careful to not be seen as 'Joe the positive person', any more than I want to be known as 'Joe the Italian guy' or 'Joe the bear'.

"I see myself as having multiple identities. To be emotionally healthy I think you have to have balance in your life and that includes not letting some of the negatives associated with HIV overwhelm you."

TWELVE COMBINATIONS AND STILL SEARCHING

Daniel has had a much rougher time with the virus than the other two guys and his story is a salutary reminder that the treatments do not work for everyone when resistance rears its ugly head.

Diagnosed with HIV in 1993, Daniel's treatment history is somewhat bizarre by today's standards. When AZT stopped working for him after about a year – an obvious sign of AZT-resistant virus which wasn't recognised or understood then by many clinicians – Daniel was given an increased dose of the drug, with his doctor arguing that he needed to live with the increased toxicity to get a clinical benefit.

That toxicity led to his first bout of hospitalisation to deal with side effects, followed by problems with liver toxicity after he tried to substitute ddI as his main antiviral.

When HAART came along in 1995, Daniel was offered saquinavir with 3TC, d4T and – amazingly – AZT as well.

In 1997 he tried nevirapine and, sure enough, got the rash and instantly had to go off it. After six months on AZT, d4T, indinavir and ritonavir he was experiencing liver toxicity and neurological side effects – what he describes as "brain burn" where his cognitive ability was so affected by the high dosages of drugs he was on he was having trouble with simple tasks, like (cont. page 9)



SPECIAL REPORT: Hepatitis C coinfection

Double trouble

For most of us, dealing with HIV is enough of a burden. But if you're also living with hepatitis C, decisions about treatment are more complex and taking care of yourself is even more important.

BY PAUL KIDD

It's a major challenge for public health authorities: a quarter of a million Australians are infected the hepatitis C virus (HCV), a blood-borne virus that can cause serious and sometimes fatal disease, typically takes decades to develop, and is notoriously difficult to treat.

For people living with both HIV and HCV (called HIV/HCV coinfection), dealing with the combined burden of two serious infections can also present significant challenges. Coinfected people face a much higher likelihood of experiencing hep C-related illness, and may be less likely to respond to hep C treatment.

Recent estimates put the number of people living with HCV in Australia at 242,000, but a 2004 study opened the possibility that the number could well be much higher – perhaps as high as 433,000. By comparison, there are only about 14,000 people living with HIV.

Similarities in the ways the two viruses are transmitted, and the degree to which the affected communities overlap, also mean that people living

with HIV/AIDS are much more likely than the wider Australian population to be infected with HCV. Around 10–13 percent of HIV-positive people have HCV coinfection.

How HIV and HCV interact

While HIV and HCV are quite similar in some ways (they are both classified as 'blood-borne infections' and can be transmitted by some of the same routes), they give rise to quite separate diseases and go about their work quite differently. Understanding the way the two diseases interact in people who are coinfecting has been a focus of research since HCV was discovered in the late 1980s.

The impact of HIV on hep C disease progression has been clear for some time, but the other side of the equation – the effect of HCV on HIV – has been the subject of more debate.

Most studies in coinfecting people have shown little impact on HIV progression – a large retrospective analysis of people who participated in the CAESAR trial of 3TC in the 1990s, for example, found that HCV coinfecting participants were no more likely to progress to AIDS or die than their mono-infected counterparts.

But questions have been raised about whether the picture would change with improved treatments efficacy leading to longer survival times for people with HIV/AIDS.

An Italian study published last November did find that coinfecting people had more rapid HIV disease progression.

But, in this and other studies, there were differences in the pattern of antiretroviral use between the mono-infected and coinfecting groups, attributed to the fact that the majority of the coinfecting patients were injecting drug users (IDUs) who were less likely to access health care.

Associate Professor Greg Dore of the National Centre in HIV Epidemiology and Clinical Research told *PL* that he believes the evidence now strongly supports the view that hep C doesn't negatively impact on HIV progression. When study data is adjusted to take injecting drug use out of the picture, he says, the impact of coinfection in studies is minimal or non-existent.

While people who are coinfecting are unlikely to experience additional challenges in managing their HIV infection, they do face a higher risk of HCV disease progression.

In HIV-negative people, the initial (acute) phase of HCV infection leads to chronic (long-term) hep C in about 70 percent of cases. Progression to severe liver disease (such as cirrhosis or liver cancer) is very slow, usually taking at least 20–40 years to develop. Many people with hep C never progress to this stage at all.

HIV-positive people tend to have higher HCV viral loads, are more likely to develop the chronic infection (around 80 percent) and are more likely to develop liver disease (around twice as likely to develop cirrhosis compared with HIV-negative people).

Progression to liver disease

can also be much more rapid in coinfecting patients, with the average time to develop cirrhosis estimated to be about ten years shorter than in mono-infected people (23 versus 32 years).

On the brighter side, there is evidence that in people with stable, well-controlled HIV infection (low or undetectable HIV viral load and higher CD4 counts) these differences are less pronounced.

"In someone who is able to maintain their CD4 count or restore their immune function through antiretroviral therapy, the risk of progression to advanced liver disease is much reduced," Dore explains.

Sexual transmission?

The degree to which sexual transmission of HCV occurs is a major area of controversy.

The vast majority of HCV diagnoses are attributed to direct blood-to-blood contact – unsafe injecting, tattooing or body piercing practices or, before screening began, blood transfusions.

But sexual transmission of the virus can occur, especially where blood is present during sex. Examples of where this might happen include some 'esoteric' sex practices, such as fisting or use of sex toys.

More controversially, there is also the possibility that ordinary anal sex could provide a more viable transmission route than vaginal sex, raising the possibility of increased rates of sexual transmission among men who have sex with men (MSM).

Recent research has been somewhat reassuring. In the

largest study to date, published in March 2005, a group of 1085 HIV-negative Canadian men were followed for a total of 2653 person-years to determine rates of hep C seroconversion.

At the start of the study, HCV infection rates were very low in participants with no history of injecting drug use (0.3%) compared with those who had injected drugs (32.9%), and only one participant – an injecting drug user who had shared needles – acquired hep C in the study period. The researchers concluded that sexual hep C transmission among MSM was rare.

Greg Dore points to this and other recent research as evidence that male-to-male sexual transmission of hep C is uncommon, at least in HIV-negative men, just as it is for heterosexual sex: "If you are an HIV-negative gay man, the risk of sexual acquisition of hep C is incredibly low," he says.

Among HIV-positive gay men, however, Dore concedes that "the question is still unanswered" and that further research is needed to establish the facts.

"There have been some reports out of London that appear to show an 'epidemic' of sexually-transmitted hep C among HIV-positive gay men, possibly associated with a syphilis outbreak," he says. "So there's some concerns about whether there's greater susceptibility for gay men who have HIV, particularly if they have other sexually-transmissible infections at the time of hep C (to page 10)

Do you experience difficulty remembering phone numbers, people's names or appointments?

Difficulty concentrating, slowed thinking, taking longer to do complicated tasks or difficulty keeping track of daily activities?

Many people with HIV report these kinds of problems, and they can be very difficult to diagnose and treat. They might be early signs of HIV-associated dementia; they might be due to drug side effects or they might simply be part of the normal ageing process. An expert neurological assessment is needed to determine the exact cause and, in many cases, a specific cause cannot be found, leaving positive people wondering what they can do to manage the problem.

This article will focus on simple natural therapy treatments that have been shown to improve cognition (thinking) and memory problems.

The first area to think of is vitamin or mineral deficiencies. These are quite common in people with HIV and, if left untreated, can cause many problems with cognition – problems that can be, incorrectly, attributed to the direct action of HIV or written off as an untreatable drug side effect.

B vitamin deficiencies, especially of vitamin B12, are one known cause of these types of problems. Deficiencies in vitamins B1 (thiamine), B2 (niacin), B12 and folic acid can all cause memory problems – and confusion, irritability and depression can all result from low levels of B1, B2 or B12. (There'll be more on natural therapy treatments for depression in a later article).

A 1990 study conducted by the University of Miami found that 34 percent of a group of 100 HIV-positive men had



You must REMEMBER THIS

either serious or marginal B12 deficiencies.

Compared to people with HIV who had normal levels of B12, those with deficiencies were more likely to have problems with short-term memory, reaction time and a visual scanning test. Encouragingly, short-term memory and cognitive ability significantly improved after supplementation with B12 injections.

The researchers concluded: "A considerable incidence of vitamin B12 deficiency occurs in even generally asymptomatic HIV infected subjects. Such vitamin B12 deficiency, even if marginal in

nature, contributes to impaired cognitive function seen in such individuals."

A more recent, 2004, American study found that 11 percent of a group of people with HIV developed a vitamin B12 deficiency within two years of their initial HIV presentation.

Supplementation with folic acid and vitamin B6 has been shown, in a group of 211 women (presumably HIV negative) to improve memory and planning ability and to improve verbal ability. The same study also found that "dietary intake of B vitamins was also associated with memory, speed of information

processing, verbal reasoning and verbal ability."

Mineral deficiencies also need to be considered. Zinc deficiency is probably the most likely mineral deficiency to cause specific memory problems but calcium and potassium deficiencies can also result in cognitive impairment while low levels of magnesium and iron can cause confusion, irritability and depression.

Other effective treatments for relatively mild cognitive and memory problems are medicinal herbs – which have been used for these kinds of problems for centuries.

Lemon balm is one. When 42 people with "mild to

moderate" Alzheimer's disease took lemon balm for four months they had a "significantly better outcome" for cognitive function than a placebo group. Agitation was also decreased by the lemon balm.

Many people are familiar with the reputation of an extract of *Gingko biloba* for enhancing memory and cognitive abilities. *Gingko biloba* is a tree, relatively common throughout Asia, which has been used in Chinese traditional medicine for many different ailments.

In one trial, 256 volunteers who had long-term fatigue engaged in a 14-week, double blind, placebo-controlled trial of a combination of *gingko* and *ginseng*. The trial found this herbal blend promoted fast, accurate thinking, improved short and long-term memory retention and reduced mental fatigue.

Another herbal blend, *Panax ginseng* combined with *Panax notoginseng*, improved memory in people who were experiencing vascular dementia (a form of dementia caused by loss of oxygen supply to the brain) after suffering a stroke.

For the best results with these or other natural treatments, I'd strongly recommend visiting a professional natural therapist – especially an acupuncturist, Chinese herbalist or naturopath.

A herb which has been shown to *worsen* memory is cannabis (marijuana) which some HIV-positive people may be using to control nausea or weight loss.

Unfortunately, marijuana's detrimental effect is worse for people with some degree of HIV-related symptoms – while having a lesser impact on people with no symptoms or who are HIV-negative.

Jim Arachne is the Complementary Therapy Treatment Officer for the Victorian AIDS Council. A referenced version of this article is available online.

Tenofovir and ddI warning

Clinicians are being advised to avoid prescribing antiviral combinations containing both tenofovir and ddI, following several clinical trials in which high levels of treatments failure were seen with this combination. The drugs' manufacturers warn that they should only be used together when "strictly necessary" and that patients should be closely monitored for signs of treatment failure and increased ddI side effects. People taking this combination of drugs are advised to contact their doctor for a review of their treatment.

Got to be perfect?

People who are starting treatment for the first time with high viral loads and low CD4 counts risk developing resistance to their treatments unless their adherence to



medication dosing is close to perfect, Canadian research shows. The large study included 1191 people starting treatment for the first time, of whom about one-quarter developed resistance within 30 months of follow up. The researchers found that higher viral loads, lower CD4 counts, and "substantial but imperfect" adherence were all predictors of resistance developing.

— J Infect Dis 191

Treatment breaks OK in some

People who have never had a CD4 count lower than 250 and who have sustained counts over 500 may be able to safely take

breaks from treatment of up to twelve months, according to a study published in the 18 February edition of *AIDS*. The 139 participants in this study had been on HAART for more than a year when they interrupted their treatment. The rate of decline in CD4 count after interruption was lower in those patients with higher nadir CD4 counts, and the investigators concluded that people who start treatment at CD4 counts of 250–350 can later interrupt that treatment safely for reasonably long periods.

Nevirapine in low-weight women

Women with low body mass index (BMI) are at increased risk

of developing potentially life-threatening liver toxicities if they take nevirapine, according to a South African study. Women in the study with a BMI below 18.5 had much higher rates of liver toxicity than those with higher body weight, leading researchers to recommend that other anti-HIV drugs be considered for women with low BMI where possible.

— J Infect Dis 191

New drug classes enter trials

The first experimental treatments from two entirely new classes of HIV drugs have entered their first human trials in people with HIV. The results of very early results of studies of PA-457, a maturation inhibitor, and L-870810, an integrase inhibitor, were reported to the Retrovirus Conference in Boston in February. Both drugs produced significant drops in viral load in very brief and small

studies. Development of L-870810 has been halted due to safety concerns, however a related integrase inhibitor is under development. Further trials of PA-457 are planned.

—Aidsmap

Insulin and 'buffalo hump'

The lipodystrophy-associated condition known as 'buffalo hump' – fat accumulation between the shoulder blades – is associated with high insulin levels, according to an Australian study. Researchers used data from the Australian Lipodystrophy Prevalence Study, a 1348-person cohort, to determine that the condition, which occurs in between two and 13 percent of HIV-positive people, is strongly associated with increased insulin levels, which may also lead to type 2 diabetes.

—Aidsmap

It's been a while since there was much cause for excitement in the drug pipeline, and even now there's just one anti-HIV drug nearing the end of the development maze. But, says KIRSTY MACHON, a new generation of HIV treatments promises to break the drought.

A few years ago, the HIV drug development landscape seemed rather barren, littered with unimpressive 'me-too' drugs, second-generation drugs from already-existing classes, noble and ignoble failures, and even one or two obscure compounds withdrawn for depressing-sounding reasons such as "unacceptable kidney toxicity in dogs."

With the notable exception of T-20 (enfuvirtide) – which did not exactly enjoy a seamless journey through the drug development phase – there were few drugs which appeared to offer a genuinely innovative or new approach to HIV treatment.

In the last two years, however, things seem to have changed: several important and promising new treatment options have appeared on the radar. This article will focus on three areas of development that seem especially encouraging, each at a different stage of development: tipranavir, a group of drugs called DAPYs, and the CCR5 attachment inhibitors.

PROTEASE: THE NEXT GENERATION

Manufactured by Boehringer Ingelheim (who also make the non-nuke nevirapine), tipranavir is a new experimental protease inhibitor (PI) which is in an advanced stage of development. It has already been extensively researched throughout the world, and several phase 3 clinical studies have delivered interim reports.

Of all the drugs in this article, tipranavir is probably the closest to the end of the development process, with marketing applications already lodged in the United States and Europe, and an Australian licensing application expected to follow in due course.

Originally developed by Pharmacia and Upjohn, tipranavir's development has been marked by several setbacks to the research process, and the compound was eventually sold to Boehringer.

It is currently available in Australia through an 'emergency access' program, and is also being provided to Australian patients who were involved in clinical studies. The emergency access program is currently very limited – much more so than has been the case with many previous drugs: only people with fewer than 100 T-cells and viral loads over 10,000 qualify for this program.



Tipranavir has been available under much less restrictive criteria to UK patients since last June, and in the US since December, and there are ongoing negotiations with the company to widen access here.

Like other PIs, tipranavir has been investigated as part of combination treatment for HIV. Unlike other PIs however, tipranavir has a novel 'non-peptidic' molecular structure which is designed to make it effective against virus which has become resistant to existing drugs in this class. The developers of this drug also hope that non-peptidic PIs will be less likely to lead to resistant virus themselves.

Because of this, the main focus of research on tipranavir (and the likely first widespread use of the drug once it becomes available) is in salvage therapy, for people who are resistant to existing treatments and in need of new treatment options.

As with other PIs, people taking tipranavir often report gastrointestinal disturbances as the most common side effect (around 45 percent of people develop diarrhoea). Tiredness, nausea, headache and vomiting can also occur.

People taking tipranavir in clinical trials have been observed to have increased liver enzymes (ALT, AST, etc) but these were usually mild and did not cause any illness or lead to people stopping the drug. Like most other PIs, tipranavir also leads to increased blood fat (triglyceride and cholesterol) levels in a substantial number of people, leading to questions about the likely long-term side effects.

DESIGNER MOLECULES: FINESSING OLD TARGETS

One of the major concerns about so-called 'me-too' drugs (which target the same parts of the HIV life cycle as existing antivirals) is the phenomenon

of cross-resistance or multiple drug resistance. Mutations to HIV which occur over time can make the virus partly or wholly resistant to not just one particular drug but several or all of the drugs in a class.

For example, resistance to any one of the current non-nucleoside drugs typically means resistance to the other two drugs in this class. So if you're resistant to nevirapine, you'll probably be resistant to efavirenz as well – which can seriously limit your treatment options for the future.

The problem with HIV is that it's a 'moving target': rapid evolutionary or genetic change creates opportunities for treatment resistance to develop. Researchers are now turning to cutting-edge chemistry to see whether it's possible to engineer drugs in such a way that it's more difficult for HIV to develop resistance to them.

There are two broad approaches which might work here: you could design drugs to more effectively inhibit mutant HIV, or you could design drugs which target the 'conserved' areas of the HIV genome – those which tend to undergo the least genetic instability and variation.

The Belgian drug company Tibotec (part of the global pharmaceutical manufacturer Johnson and Johnson) is pursuing the first approach, setting out in ardent pursuit of new chemical compounds which might be effective against resistant virus.

These drugs target the same parts of the HIV life cycle as existing drugs, but they are designed to incorporate a degree of 'molecular flexibility' that would enable them to accommodate small genetic changes in the target areas of the HIV genome, making it harder for HIV to become resistant to them.

The first of these drugs to undergo clinical trials was a

protease inhibitor called TMC114, which has gone through several phase 2 studies (including in Australia) and is expected to start phase 3 studies soon. Early data suggests that TMC 114 remains effective in people who have high-level resistance to other protease inhibitors.

Tibotec is also involved in the development of TMC125, a non-nucleoside reverse transcriptase inhibitor (NNRTI). An NNRTI which remains active against virus which is resistant to other NNRTIs would be a particularly valuable addition to HIV treatment. This is because of the very real problem of class resistance in the NNRTI group. The two main drugs in this class, nevirapine and efavirenz, are both highly important because they are often more tolerable than protease inhibitors, and they have good activity against HIV.

Johnson and Johnson and Tibotec are also looking at a new group of NNRTIs called DAPYs. DAPYs, short for diarylpyrimidines have been developed at New York's Rutgers University using cutting-edge molecular modelling techniques to target HIV in such a way that they could overcome some of the problems faced by older HIV drugs (like poor bioavailability and long half-lives, and limitations in the formulations which make it easier for HIV to mutate around).

These still-experimental drugs are still at the very earliest stages of development, but the early results of test-tube studies have been staggering, with single drugs suppressing HIV as effectively as existing three and five drug combinations, and with inbuilt molecular flexibility that enables them to adjust to changes in the virus's molecular structure. Professor Eddy Arnold, one of the

leaders of the Rutgers team, described the DAPYs as "rolling with the punches, wiggling and jiggling around" to fit the unique molecular makeup of each HIV particle.

DAPYs are a long way from becoming part of routine therapy (just getting them this far has taken over ten years) but they give a glimpse of the changing ways in which drugs are developed. As a recent article in the *Journal of Medicinal Chemistry* enthused: "The discovery . . . was the result of a coordinated multi-disciplinary effort involving medicinal chemists, virologists, crystallographers, molecular modellers, toxicologists, analytical chemists, pharmacists, and many others."

ATTACHMENT INHIBITORS: FINDING NEW TARGETS

Before HIV can enter and infect individual cells, it must first attach itself to the cell surface. It does this in several steps, first by binding to a chemical marker called CD4, then to one of two chemokine receptors, called CCR5 and CXCR4. Once HIV has locked on to two points, it is able to break into the cell.

Drugs that interfere with this process by locking onto the CCR5 or CXCR4 'co-receptors' before HIV gets to the cell are called 'attachment inhibitors'. Two drugs in this class, both of which work on the CCR5 co-receptor, are about to enter clinical trials.

A phase 2 study of Pfizer's CCR5 inhibitor, codenamed UK-427,857, is enrolling now in Australia. A second CCR5 inhibitor, being developed by GlaxoSmithKline, is likely to follow into trials soon.

These drugs do raise some important questions. In particular, there are some concerns that these drugs do not prevent HIV from attaching to the alternative CXCR4 chemokine receptor. While most HIV strains prefer the CCR5 route, virus which uses CXCR4 – usually only seen in the later stages of HIV disease – is believed by some researchers to be more virulent.

ONE VIRUS, MANY TARGETS

Perhaps the most encouraging aspect of the HIV drug development pipeline at the moment is the proliferation of drugs designed specifically to combat the problem of resistant virus, such as tipranavir, drugs with novel molecular structures, such as the DAPYs, and drugs targeting whole new stages of the HIV cycle, such as the attachment inhibitors.

If the promise of these new compounds is borne out by clinical trials (and, let's be honest, history tells us that many more HIV drugs are abandoned than ever make it to market), it's just possible that the face of HIV treatment will undergo a change as radical as that of the 'Protease Moment', with a new capacity to target HIV not just with me-too drugs offering incremental benefits and the risk of cross-class resistance, but at the many points of its complex and complicated life cycle.

With Australia's nearest neighbour, Papua New Guinea, facing the possibility of a catastrophic HIV epidemic, Australian AIDS activists are working with local positive people to ensure their voices are heard.

The head of the United Nations' AIDS agency, Dr Peter Piot, has said he is alarmed by the apparently uncontrolled spread of HIV in Papua New Guinea.

Speaking at the Asia-Pacific Leadership Forum on HIV/AIDS and Development in Port Moresby in February, Dr Piot described PNG as "a new frontline of the AIDS epidemic," and said he was shocked at the rapid growth in the number of people infected in the country, especially women.

Against this background, Australia's National Association of People Living with HIV/AIDS (NAPWA) has been working with the country's HIV-positive community since 2002.

A key milestone for the PNG positive community came in November 2003 with the formation of the country's first representative organisation for people living with HIV/AIDS, Igat Hope (the name means 'there is hope' in Tok Pisin).

The organisation's founding followed the 2003 NAPWA conference in Cairns, which was attended by a large delegation of people from PNG, and since then, NAPWA has been actively involved with Igat Hope, providing peer support, mentoring and guidance to assist the fledgling organisation.

Currently operating in Port Moresby but with plans to expand to other cities and eventually become a truly national organisation, Igat Hope's objective is to give positive people a unified voice – to lobby government, provide information, promote



'I'm not afraid – I have protection!' reads the caption on this AIDS awareness poster at the entrance to the AIDS ward of Mount Hagen General Hospital in PNG.

PHOTO: AAP IMAGE/AFP/TORSTEN BLACKWOOD

There is hope

BY PAUL KIDD

access to treatment and care, and fight stigma.

The group has been granted funding from the UN Development Program and is working with NAPWA to develop a constitution, develop advocacy skills and organisational capacity.

With funding from the Australian government's overseas aid program AusAID, NAPWA representatives have visited PNG twice in recent months, once in August last year and again in January.

PNG may be geographically close to Australia, but the country's experience of HIV/AIDS is shaping up to be worlds apart. While the most recent UNAIDS figures, for the end of 2003, put the number of people living with the virus at around 16,000, there is

evidence that the number is much higher – as many as 100,000 of PNG's 5.4 million people could be infected, and the epidemic is said to be spreading rapidly, fuelled by extreme poverty, violence against women, and internal migration.

It sounds very much like a recipe for disaster, and indeed it is – for some years, warnings of the possibility of an Africa-style epidemic in PNG have drawn only a lukewarm response from the country's government. Now there are fears that with the HIV epidemic becoming generalised within the country, there is little that can be done to avert a catastrophe.

The enormity of the threat to PNG was emphasised by Dr Piot. "It's about the survival of

the nation," he told the Leadership Forum.

At a function to officially launch Igat Hope, Dr Piot said the establishment of a national PLWHA organisation was a "defining moment for the response to AIDS in Papua New Guinea."

NAPWA's International Portfolio Convenor, John Rock, agrees that the formation of a national advocacy organisation is a key milestone. While local organisations and drop-in centres are best placed to deliver services on the ground, he said: "Igat Hope is the only body which is really going to represent PLWHA voices at a higher-order level."

"I would hope they would have a greater voice in policy, with the National AIDS Council, that they should be

involved with the Global Fund." The challenges facing Igat Hope are considerable, Rock acknowledged. "Not only do you have a lot of ethnic diversity, but you also have geographic isolation," he said. Internal communications within PNG are very poor: Port Moresby – the capital and largest city – is unconnected by road to other major cities, making transport slow and expensive.

While government and non-government organisations are committed to responding to the growing AIDS problem, the challenge, said Rock, is "to decide what is the best way to use that funding given that the infrastructure to deliver things like treatment and services is not well-established."

For individual positive people, the immediate urgency for most people is simply getting food and shelter, said Rock. "Most positive people don't have a job, they have no prospects of one and they have little or no income," he said.

In a country with chronic underemployment, no welfare system and where general health is very poor to begin with, the added stigma of being HIV positive creates a substantial burden. HIV testing levels are very low – tests are not easily available – which means that most positive people become aware of their HIV status only when they or their spouse become too sick to work.

"The difficulty is that PNG is a very complex and very specific society with many social and economic problems," said Rock. "The willingness of external agencies is there to assist, and I daresay there is a recognition in the government of the seriousness of the problem. What everybody's struggling with is what is the best way forward to try to achieve something in a timeframe which is effective before the problem gets much much worse."

BY GABE MCCARTHY

Arriving in Port Moresby, you are immediately reminded that HIV in PNG is very different to Australia. Large billboards proclaim *Lukautim HIV* ('watch out for HIV') and the radio on the short drive to the hotel played ads about HIV.

While I knew that PNG is facing an African-style epidemic, seeing these immediate signs that HIV is a political and social priority (in a way that it never has been in Australia) really brought home that I am working in a very different environment to the one I'm used to. Certainly being President of NAPWA opens doors in a way that would never happen in Australia, and it is a seductive experience to be in a country where HIV is a priority.

There are many other differences too, however, and certainly some mean I would never want to be in the shoes of people living with HIV in PNG. The absence of tests and

LUKAUTIM HIV

treatments that we take for granted, like CD4 counts and viral loads, or even simple things like affordable anti-diarrhoea medicines, really hit home when I spent time with Igat Hope members.

It can be easy to get distracted by the day-to-day realities of living with HIV in a resource-poor setting, to feel overwhelmed by the level of need experienced by positive people living in a country without modern health infrastructure or a social security system.

Certainly this has challenged the social activist in me, as I am considered to be one of the many positive people living in poverty in Australia, but in PNG I am better off than most positive people who are working.

Staying focused on the reason why I was in PNG – to assist the positive people who had established Igat Hope to get the organisation off the

ground – is a useful way to deal with these challenges. Ensuring that positive people in PNG have a strong and effective organisation that can advocate for better services is going to make a far greater difference in the response to the epidemic than anything else I could individually do.

Working with the active members of Igat Hope, I was struck by just how important peer support is for positive people when there are few other services available. The strength of the positive networks was evident everywhere I went, being introduced to 'friends' (the term used to discreetly refer to a positive person) at every turn.

This was perhaps the most striking impression I had on this trip, perhaps because this was my second journey to Port Moresby and I was more able to look past the social inequities and just connect with

positive people more as a peer.

My most treasured time from this last week in Moresby would have to be the Saturday that I spent working and socialising with Igat Hope members. We shared our stories and I heard just how important the positive people who had first been open about their HIV were to others in the group. I also heard the determination of many to continue to ensure that this same peer support becomes more widely available for positive people throughout the country.

There are many challenges ahead for Igat Hope, not least of which is to forge an identity in the sector where many still don't understand the concept of a positive advocacy organisation.

But even in the few months since my last trip, I can see that many service providers have developed a greater understanding of the role of

positive advocacy and become supporters of Igat Hope. While there are often misunderstandings about the role and purpose of the organisation, its members remain committed to ensuring that positive people have a voice. This determination continues to grow as more positive people experience prescriptive and judgemental service provision.

Igat Hope literally means 'there is hope' – hope for those infected with and affected by HIV. Igat Hope members are just like any other group of positive people I've worked with, and like the PLWHA movement everywhere, the movement in PNG is driven by the personal experience of positive people and our desire to be free to enjoy getting on with our lives.

I always come away from PNG full of hope for Igat Hope and for the place of positive people in the response to HIV in PNG.

■ Gabe McCarthy is the President of NAPWA. The views expressed in this article are the author's own.

A

fter 20 or so years living with HIV I finally had to bite the bullet. It was time to make the big decision.

My counts weren't as good as they had been and my doctor advised that they weren't going to get any better. How long could I wait? As it turned out, not that long. A few more tests and it was clear I was indeed getting to a point that I really had to consider starting.

I had kept up with the latest in treatments for HIV so I knew all about the problems associated with them, however things have been getting better these days. The newer drug combinations consist of fewer pills and fewer immediate side effects. While the older protease inhibitors are implicated with long term side effects such as lipodystrophy, newer drugs are just as potent but seem to be less of a problem.

My doctor suggested that I start on Kaletra, a relatively new protease inhibitor, plus 3TC and tenofovir.

I said I would really rather not start with a protease – I just couldn't bear the thought of having to deal with body changes. Not that I'm your muscled buffed Adonis – I do have a bit of a belly anyway and I'm a bit on the heavy side (brought up on way too much Italian food) but my shape is at least proportionate.

So I asked, how about efavirenz? I knew this non-nucleoside reverse transcriptase inhibitor (NNRTI) seemed not to increase blood lipids as much as the proteases, so there was hopefully less chance of lipodystrophy developing. He was OK with that.

I also felt pretty good actually being able to have that negotiating power with my doctor. I felt empowered.

The combination was pretty simple. Three pills, once a day, at night. No strict food or liquid restrictions either. Also there didn't seem to be any side effects from the 3TC and tenofovir.

The place of HIV in your life

CONTINUED FROM PAGE 4

crossing the road.

During all this, Daniel says he was lucky to be working in the HIV sector in a job where it was permissible to have a nap late in the afternoon when his morning dose was starting to peak. It was only when therapeutic drug monitoring came in that his doctor realised he was on excessive doses of some drugs and started to lower the amounts.

Resistance testing was also done on his blood to reveal that he was resistant to pretty much all the antivirals available – a consequence of some bad treatment decisions (as we now realise) made early in the piece.



Getting started on treatments is never easy. And sometimes, as SAM PESCI found, it takes a concerted effort to fit treatments into your life.

However my first few days were still difficult – I had trouble sleeping. Was my body simply getting used to the efavirenz? Unlike many of the other drugs, efavirenz affects the central nervous system. In one way it is an advantage: it crosses the blood-brain barrier and can therefore reach the HIV that collects in pockets in the brain and elsewhere in the central

nervous system.

The disadvantage is that it can leave you with a funny feeling – like being drunk and 'speedy' at the same time.

Anyway, some mornings were OK but others left me with the feeling of a hangover but without the fun night before it. This went on for about six months.

Then I remembered my GP telling me about how having a

heavy and late meal just before taking my pills could accentuate these side effects. The idea was to have a light meal or at least have the meal and wait two or three hours for the food to digest properly before taking the pills.

"Shit!" I thought. "I can't live my life from now on worrying about this."

I thought it was bad enough having to get used to taking

In 2000, Daniel made a big decision. He was faced with the option of going on seven drugs given his resistance patterns. While his T-cells were around the 600 mark, he knew that there was a chance if he took a treatment break that his virus might revert to 'wild type' and improve his chances on future regimens.

His doctor was supportive of a break as long as Daniel monitored his results. That was four years ago and he has remained on the break ever since, with surprisingly good clinical markers until recently. He is now in line to join the CCR5 inhibitor trial due to start shortly. He is looking forward to resuming treatment, because going on such a long break has its scary moments: he was never quite certain he was doing the right thing and if he was likely to get

"I had the worst thing happen at a sauna about five years ago."

sick suddenly.

Daniel made a lifestyle change at the same time as he started his treatment break, moving to a quiet outer suburb of Melbourne and living on a small farm with his partner. It worked well, he found himself a good job but he needed the company of positive peers from time to time. He sought out positive contacts at PLWHA Victoria and in the gay community to share

anecdotes about what was the latest on treatments and HIV and to keep things in perspective.

"I've needed some support from pos people who understand what I'm going through. Some friends can't understand that I don't have the energy to go out some nights – even some positive people who are going well on treatments don't quite know what my experience is like.

the pills every night in the first place. Now I had to take them in a certain way.

It was hard since all my life I've simply lived the way I wanted to. I can't remember how many times I've left a bar or club late at night or early in the morning and stopped on the way home to pick up a pizza or souvlaki. But at the same time I was really getting tired of those 'off' mornings so I decided, OK, I'm going to make a concerted effort to do what I could.

So I started eating a lighter meal or at least eating earlier and waiting two or three hours before popping those pills just before going to sleep.

It has made a big difference. I'm feeling much better in the mornings; I feel the worst is over.

In the meantime my viral load has remained undetectable. My T-cell count has been rising too, but not as fast as the viral load dropping. My doctor said that while viral load can change dramatically, T-cell counts take just a little longer.

There are many combinations and, of course, everyone is at a different stage with HIV and may not have so many options. However it seems that for me, someone who had started treatments for the very first time or what the medicos call "treatment naïve", I could not have picked a better one – despite the time it took to get on top of the side effects.

Am I glad I'm on treatments? I could say that there is no use in thinking about it that way, since I didn't have much of a choice, but I think I am. I look at it as a positive action that I have taken in my life in terms of gaining better health. I have more energy and, psychologically, I feel better knowing that my viral load is undetectable and my T-cell counts are slowly on the up.

My doctor believes that if I minimise the number of missed doses then this combination can last for years. That sounds pretty good to me.

■ Sam Pesci (not his real name) lives in Melbourne.

HIV is different for everybody and you really can't generalise about what it's like for all people with the virus."

After talking to these three people, I have to agree with Daniel's point. Living with HIV is a complex and varied experience with no one path that even the majority would seem to follow. It's true that some of us are still doing it tough but even then, I think most would agree that it's worth trying to not let it dominate your life too much or to interrupt your achievement of some of the life goals you set yourself. With all the optimistic news on the treatment front just now, we should be enjoying life as if there will be a tomorrow!

* Names and other identifying details in this story have been changed.

Positive Living

ISSN 1033-1788

EDITOR

Paul Kidd

(paul@napwa.org.au)

ASSOCIATE EDITOR

David Menadue

CONTRIBUTORS

Nicola Addison, Jim Arachne,

Kirsty Machon, Gabe McCarthy,

David Menadue, Sam Pesci

DESIGN AND LAYOUT

Stevie Bee Design

Positive Living is a publication of the National Association of People Living with HIV/AIDS.

napwa

Positive Living is published six times a year. Our next edition will be published in April 2005.

Positive Living is distributed with assistance from



Subscriptions

Free subscriptions are available to HIV-positive people living in Australia who prefer to receive *Positive Living* by mail. To subscribe, visit our website or call 1800 259 666.

Contributions

Contributions to *Positive Living* are welcome. In some cases, payment may be available for material that we use. Contact the Editor.

Address correspondence to:

Positive Living
PO Box 51 Newtown NSW 2042
Tel (02) 9557 8825
Freecall 1800 259 666
Fax (02) 9557 9461
e: pl@napwa.org.au
NAPWA website
www.napwa.org.au
Free audiotapes:
Positive Living on tape
Tel. (03) 9525 4455

Positive Living is a newspaper for all people living with HIV/AIDS in Australia. Contributions are welcomed, but inclusion is subject to editorial discretion and is not automatic. The deadline is 14 days before publication date. Receipt of manuscripts, letters, photographs or other materials will be understood to be permission to publish, unless the contrary is clearly indicated.

Material in *Positive Living* does not necessarily reflect the opinion of NAPWA except where specifically indicated. Any reference in this publication to any person, corporation or group should not be taken to imply anything about the actual conduct, health status or personality of that person, corporation or group. All material in *Positive Living* is copyright and may not be reproduced in any form without the prior permission of the publishers.

The content of this publication is not intended as a substitute for professional advice.

exposure," he says.

One possible explanation for this is the fact that HIV/HCV coinfecting people often have higher HCV viral loads than those with HCV alone. Additional risk factors could include sexual practices with greater likelihood of blood-to-blood contact (such as fisting and sharing sex toys) as well as concurrent STIs, especially syphilis.

For sexually active HIV-positive people who wish to protect themselves from hep C, Dore reiterates that he believes the risk is not high, but concedes that it is "somewhat unknown, and it could be significant." HIV-positive men who have negotiated unprotected sex with positive partners should be aware that there may be "a small risk of hep C transmission" if their partner is hep C positive, he says.

"To be honest, I think the risk is low," he says, pointing out that the risk of more common STIs such as syphilis or gonorrhoea is much higher.

Treatment and care

An important question is whether to treat HIV or HCV first. Until a few years ago, most clinicians took the view that because HIV is likely to become life threatening sooner, it should be the first priority in treatment.

Doctors now recommend different courses of action depending on the individual patient's circumstances. HIV often remains the first priority, especially as people with higher CD4 counts may respond better to HCV treatment and may be less prone to side effects.

The only treatments currently available for hep C consist of interferon or pegylated interferon combined with ribavirin.

Interferon is a naturally occurring protein produced in the body in response to viral infection. Synthetic interferon has been used for some years in treatment of hepatitis C, as well as some other infections and cancers.

Pegylated interferon is a modified form which makes the interferon last longer in the body. There are two different pegylated interferons available under the PBS: Roche's *Pegasys* and Schering-Plough's *Peg-Intron*, both of which are given by injection.

The second drug in the combination, ribavirin, is an antiviral medicine which comes in tablet or capsule form.

Like HIV medications, these expensive and highly specialised medicines can only be prescribed by specially licensed physicians and are subject to strict eligibility criteria.

Access to hep C combination treatment is available to coinfecting patients in Australia under the same criteria as for people with HCV alone: they must have documented chronic hep C, elevated liver enzymes, and some evidence of liver fibrosis – scarring of the liver tissue.

Double trouble

continued from page 5

Fibrosis, the key measure of liver disease progression, is determined via a liver biopsy, in which a small amount of tissue (about the size of half a matchstick) is removed through a needle inserted into the liver, and studied under a microscope.

Dore is hopeful that the requirement for a liver biopsy will be relaxed in the next 6–12 months: while biopsy remains an important tool in hep C management, he is concerned that the invasive and sometimes painful procedure is a barrier to patients considering treatment. "I think a lot of people are still holding back because of the liver biopsy requirement," he says.

Results from two major international studies of hepatitis C treatment in coinfecting people – APRICOT and ACTG 5071 – were published last year.

The largest of these, the APRICOT study, included 860 coinfecting people in 19 countries, who were divided into three arms:

- Standard interferon three times weekly, plus daily ribavirin.

- Pegylated interferon (*Pegasys*) once weekly, plus daily ribavirin.

- *Pegasys* once weekly, plus placebo.

After 48 weeks, the numbers of patients in each arm who achieved a 'sustained virological response' (SVR) – essentially an undetectable HCV viral load – were 12, 40 and 20 percent respectively.

The effectiveness of the treatment was better for HCV genotypes 2 and 3 (62 percent in the *Pegasys*/ribavirin arm) than for genotype 1 (29 percent).

While lower than the response rates seen in HCV-monoinfecting patients with the same treatment, these are some of the best-ever trial results in people coinfecting with both viruses, and "demonstrate that the current regimen used for the treatment of chronic hepatitis C alone can also be applied to patients coinfecting with HIV and HCV," the researchers concluded.

The second study, ACTG 5071, enrolled 133 coinfecting patients in the US who received either standard or pegylated interferon, plus ribavirin. Response rates after 48 weeks were similar to the APRICOT study, however after 72 weeks the response rate in the pegylated arm dropped to 27 percent due to large numbers of relapses, especially among patients with genotype 1. Possible explanations for this include the lower dosage of ribavirin used, and the different racial characteristics of the participants.

An interesting finding of the ACTG trial is that anti-HCV

therapy is beneficial even when a sustained virological response can't be attained – liver biopsy results showed that 35 percent of participants had improvements in fibrosis, regardless of whether there was a virological response.

In Australia, Greg Dore says treatment results for coinfecting patients have been very good: "At the St Vincent's Hospital Hepatitis Clinic we're running at a sustained virological response rate of above 60 percent, which is better than any of the clinical trials, and as high as 75 to 80 percent in people with genotype 2 and 3," he says. Even for genotype 1 (the most common type in Australia) the response rate has been better than 50 percent, according to Dore.

"In fact, there's very little difference in terms of our response rates between those who are coinfecting and those who are monoinfecting," he says.

While these results have been important in demonstrating that anti-HCV treatment is viable and (at least partly) effective in people coinfecting with HIV, there is clearly some way to go before we have hepatitis C treatments with similar efficacy as those we now have for HIV/AIDS.

Several pharmaceutical companies are currently working on experimental protease inhibitors for HCV, however to date human trials have proved disappointing. Greg Dore remains hopeful, however, that new HCV treatments will start to become available within 3–4 years.

"There's a lot of development out there, but we're probably stuck with pegylated interferon and ribavirin, possibly with the addition of another agent that might slightly increase response rates, for the next three or four years," he says.

The decision to start hep C treatment can be a complex one, especially for HIV coinfecting patients. Hep C genotype, baseline HCV viral load, and levels of liver fibrosis are all factors that can influence the decision. Dore points out the importance of also taking into account the individual's personal circumstances – their employment, social and family situation – in making the decision to go through "what can be a pretty difficult six or 12 months of treatment."

The side effects of hep C treatment – both physical and mental – can be debilitating, so it's important to choose the right time to treat.

The individual's HIV disease status – CD4 count and viral load – can also affect the decision. People with very advanced HIV disease may benefit from delaying hep C

treatment until their immune system recovers, as there is evidence that people with higher CD4 counts respond better to hep C treatment. But Dore points out the difference in response rates levels off quickly for people with even moderate-range CD4 counts: "I don't think there's a lot of difference between a CD4 count of 250 and 550 – response rates to hep C treatment are very good across all those strata," he says.

Once people have started treatment, Dore points out the importance of strong support for patients as a reason why Australians seem to do better on treatment than people in other countries. Early detection and treatment of depression, peer support and involvement of social workers all help people stay on treatment and improve outcomes.

Dore is a strong supporter of peer support for people going on treatment, and says the encouragement, understanding and camaraderie gained by people in support groups is invaluable.

Taking action

While treatments are improving and can be expected to improve further in the future, in the meantime there are worthwhile steps anyone can take – whether coinfecting or not – to maintain their health.

If you're HIV positive and you're sexually active or have ever used intravenous drugs (whether or not you've shared needles), you should be tested for hep C. Early detection increases the options for treatment and makes it possible to make lifestyle changes to protect your liver from damage.

There is no vaccine for hepatitis C. The best way to avoid becoming infected is to avoid high-risk behaviours, including unsafe injecting practices, unsterile tattooing or body piercing, or any activity which could allow direct blood-to-blood contact. Wear latex gloves for fisting, don't share sex toys and practice safe sex.

If you are coinfecting, talk to your doctor about treatments, and ask to be referred to a liver specialist with experience in HIV coinfection. Get vaccinated for hepatitis A and B, and reduce the intake of substances which could harm your liver, such as alcohol, recreational drugs and fatty foods. Maintain safe behaviours to protect others and yourself (reinfection with a second HCV genotype is possible and can significantly reduce treatment effectiveness).

An AIDS Treatment Project Australia fact sheet on hep C coinfection is available from NAPWA or can be downloaded from our website (www.napwa.org.au).

■ A referenced version of this article, and links to other resources for coinfecting people, are available online.

The number and variety of anti-HIV treatments expands almost every year. There are

now 19 different HIV medications available on the Pharmaceutical Benefits Scheme, and more are in various stages of development.

Most readers will be aware that, to be effective, antiretroviral combinations typically include at least three different drugs from at least two different drug **classes**. The drugs we have available now are classified into four classes, but new drugs are being developed which will expand the number of drug classes and promise to radically improve the effectiveness of anti-HIV therapy.

In this *Backgrounder* we take a look at what drug classes are, and how they target HIV at specific points in its life cycle.

The circle of HIV

Once HIV has entered the human body, it follows a very specific routine: infecting cells, making new copies of itself, which then seek out new cells to infect. Like all viruses, HIV cannot replicate by itself – it needs a **host cell** to reproduce.

The reason for this is that viruses are incredibly simple organisms. In fact, HIV has just nine genes which carry all the genetic information which enables HIV to go about its dastardly work. By comparison, human DNA contains somewhere between 20,000 and 35,000 genes.

With so few genes, the HIV genome simply doesn't have enough storage room to carry the instructions it would need to reproduce like other organisms – just as you can't run a word-processing computer program on a pocket calculator.

Because of their simplicity, and their inability to reproduce without outside help, there's an ongoing scientific debate about whether or not viruses are truly 'alive'. But alive or not, HIV is plainly capable of reproducing, spreading from person to person and wreaking terrible damage along the way.

The key to this is the sophisticated and carefully choreographed ballet which the virus performs, once it gets into the human bloodstream, to infect cells, take over the cell's internal processes, and turn them to its own purpose.

The process can be divided into five discrete stages; HIV drugs work by interrupting the virus's work at any one of these. The particular stage at which the drug works defines which class that particular treatment falls into.



A touch of class

HIV drug classes and targets

Let's look at each of these stages – and the drug classes that target them – in turn.

Entry

Once it has found its way into the human body, the virus needs to locate and enter a cell before it can reproduce. HIV targets a specific type of cell, called a CD4 cell, which is part of the immune system.

Gaining entry to a human cell from the bloodstream probably doesn't sound too hard – after all it's just a tiny speck of protein, water and DNA. But in the microscopic world in which HIV operates, it's actually no picnic. Human cells may be very tiny, but they have evolved with a tough outer coat which is designed specifically to keep intruders like HIV out.

So HIV can't just knock on the door and waltz inside, it has to pick the lock.

To do this, a chemical on the virus's surface called **gp120** first binds (attaches to) not just one, but two chemicals on the surface of the cell. The first is CD4 (after which the cell is named); the second can be either of two different chemical markers called **CCR5** and **CXCR4** ('R5' and 'X4' for short). HIV then uses another protein called **gp41** to penetrate the cell membrane and get to work.

All those numbers and letters may look like alphabet soup, but it's helpful to

understand them because they suggest different ways that **entry and fusion inhibitors** could work. To stop HIV at the entry stage, drugs could be developed to target HIV surface proteins (gp120 or gp41) or CD4 cell co-receptors (R5 or X4). By attaching to any of these points before HIV gets into the cell, they could interrupt the HIV cycle in the same ways that putting chewing gum into a lock interrupts someone trying to open a door.

We currently have one approved drug in this class – the fusion inhibitor **T-20**, which works by attaching itself to gp41. Drugs are currently in clinical trials to target the R5 co-receptor (called CCR5 inhibitors – see page 7 of this issue for more on these) and the gp120 protein has been the target of some (unsuccessful) vaccine research.

Reverse transcription

Once it gets into the cell, HIV has to insert its own genetic code into that of the host, reprogramming it from being an immune system cell to being an HIV factory. Before this can happen, HIV has to perform an extraordinary trick.

The human genetic code, found in the nucleus of every cell in your body, is recorded on two long chains of DNA. HIV's genetic code is recorded in a single short strand of RNA, so HIV has to convert

the RNA to DNA before it can hijack the cell. This process is called 'reverse transcription' and depends on an enzyme (a type of protein) called **reverse transcriptase**.

Drugs which interfere with the reverse transcriptase enzyme are called **reverse transcriptase inhibitors** and they come in three different flavours:

- nucleoside analogue reverse transcriptase inhibitors (NRTIs, or 'nukes') such as AZT, ddI, d4T, ddC, 3TC, abacavir and FTC.
- non-nucleoside analogue reverse transcriptase inhibitors (NNRTIs, or 'non-nukes') such as efavirenz, nevirapine and delavirdine.
- nucleotide analogue reverse transcriptase inhibitors (NtRTIs) such as tenofovir.

Each type works in a slightly different way, but they all interfere with the reverse transcription process. Unable to convert its RNA into DNA, HIV cannot reprogram the cell to make more copies of itself.

The nucleoside and nucleotide drugs, while chemically different, are usually grouped together as one class for the purpose of making treatment decisions, while the non-nukes are in a class of their own.

Integration

After converting RNA to DNA

(and then converting the resulting single strand of DNA to a double strand) the HIV DNA must be inserted into the human DNA. This process, called integration, is achieved with the help of another HIV enzyme, **integrase**.

There has been some research into drugs that would interfere with this stage of the HIV cycle – indeed, several years ago there was a great deal of hype about **integrase inhibitors** – but so far the results have mostly been disappointing. This drug class seems especially hampered by toxicity problems, but research is continuing.

Cleavage

Once the viral DNA has been inserted into the host cell's nucleus, the cell starts producing copies of HIV. But, like Swedish furniture, some assembly is required.

The newly-repurposed CD4 cell produces long chains of proteins, which must be cut up and reassembled in the right order before they become new HIV viruses.

This process is called cleavage, and it depends on an enzyme called **protease**, which acts as a kind of molecular 'scissor' to chop up the long chains.

Drugs which interfere with this process are called **protease inhibitors** (PIs). There are seven PIs currently approved for use in Australia: saquinavir, indinavir, ritonavir, amprenavir, nelfinavir, lopinavir and atazanavir.

Assembly and budding

Finally, the new virus particle (**virion**) is assembled from the pieces prepared during the cleavage process. This stage is called **assembly** or **maturation**.

Drugs that target this stage of the HIV cycle are called **maturation inhibitors**. So far, only one drug in this class, called PA-457, has entered preliminary clinical trials.

By this stage (if the process has not been halted by anti-HIV drugs at any of the earlier stages) the new HIV virion is ready to graduate to the big time, and start the process over again with a new CD4 cell. The virion moves to the surface of the cell and breaks through into the bloodstream. As it does so, it takes with it a small piece of the cell membrane. Over time, the cell membrane weakens and eventually the process destroys that CD4 cell.

As you can see, the large range of HIV drugs we have now are still only targeting a few of the possible points in the HIV cycle. Research is continuing on drugs that promise to improve options for HIV therapy by increasing the number of stages in the HIV cycle we can target.

– Paul Kidd

PLWHA Broadsheet

NATIONAL

- **National Association of People Living With HIV/AIDS (NAPWA)** ☎ 02 9557 8825 or 1800 259 666 ☐ www.napwa.org.au
- **Australian Federation of AIDS Organisations (AFAO)** ☎ 02 9557 9399 ☐ www.afao.org.au
- **Australian Hepatitis Council** ☎ 02 6232 4257 ☐ www.hepatitisaustralia.com

NEW SOUTH WALES

- Area code (02)
- **PLWH/A (NSW) (M) (V)** Advocacy, services, publications, speakers' bureau, events. Suite 5, 94 Oxford St Darlinghurst. ☎ 9361 6011 or 1800 245 677 ☐ www.plwha.org.au
 - **ACON (M) (V)** HIV prevention, health promotion, advocacy, care and support services for PLWHAs, gay men, lesbians, ATSI, IDU, sex workers. 9 Commonwealth St Surry Hills ☎ 9206 2000 or 1800 063 060 ☐ www.acon.org.au
 - Treatments Info ☎ 1800 816 518
 - Counselling ☎ 1800 647 750
 - Positive Women ☎ 9206 2015
 - Western Sydney ☎ 9204 2400
 - Hunter (Newcastle) ☎ 4927 6808
 - Illawarra (Wollongong) ☎ 4226 1163
 - Northern Rivers (Lismore) ☎ 6622 1555 or 1800 633 637
 - Mid-North Coast (Port Macquarie) ☎ 6584 0943
 - **Community Support Network (CSN) (V) Transport + practical home help for PLWHAs.**
 - Sydney ☎ 9206 2031.
 - West Syd/Blue Mtns ☎ 4734 3887.
 - Hunter/Mid Nth Coast ☎ 4927 6808.
 - Illawarra ☎ 4226 1163
 - CSN volunteers (training provided) ☎ 9206 2038
 - **Ankali (V)** Volunteers provide one-to-one emotional support for PLWHAs, their partners, family and friends. Referrals, counselling, professional support. ☎ 9332 9742
 - **Positive Living Centre Sydney (PLC) (M) (V)** Regular programs, social events, meals, service info, referrals, care coordination, complementary therapies, internet access, re-skilling, art classes. Tue-Sat 10-4, 703 Bourke St Surry Hills ☎ 9699 8756
 - **Luncheon Club (V)** Free lunch (Mon 12-4) for people living with and affected by HIV and Luncheon Club Larder (Mon/Wed 12-4) Free food + essentials for PLWHAs struggling on the DSP. 77 Kellick St Waterloo ☎ 8399 3220 or 0416 040 074 ☐ luncheonclub.org.au
 - **Bobby Goldsmith Foundation (BGF) (V)** Financial assistance with essential bills, no interest loans, financial counselling, support with study and employment and supported accommodation ☎ 9283 8666 or 1800 651 011 ☐ www.bgf.org.au
 - **Positive Futures Project** Support for people considering returning to work or study, volunteering and alternatives to paid work. ☎ 9283 8666 or 1800 651 011 ☐ www.bgf.org.au
 - **HIV/AIDS Legal Centre** Free HIV-related legal services. Wills, superannuation, immigration, discrimination ☎ 9206 2060 or 1800 063 060 ☐ www.halc.org.au
 - **Multicultural HIV/AIDS + Hepatitis C Service** Bilingual/bicultural support, advocacy for people from non-English-speaking backgrounds. ☎ 9515 5030 or 1800 108 098 ☐ www.multiculturalhivhepc.net
 - **Positive Central** Counselling, dietetics, occupational therapy, physiotherapy. Individual and group sessions, home visits. ☎ 9395 0444
 - **Switched On Living** Monthly information sessions about healthy lifestyle for PLWHAs, friends, family, carers. ☎ 8382 2072
 - **PozHet (HIV Positive Heterosexuals) (M)** Freecall counselling for positive straight men, women & partners. Women's officer avail. Annual Calendar of fun & support activities. ☎ 1800 812 404 ☐ www.pozhet.org.au
 - **The Sanctuary (V)** Complementary therapies, massage, shiatsu, yoga ☎ 9515 6142 ☺
 - **North AIDS** Supported accommodation for PLWHA and carers. Info and day centre at Myrtle Place (M-F 9.30-4.30 or by arrangement). Lunch, social activities,

- massage, counselling. For a copy of the monthly calendar ☎ 9929 4288
- **Fit X Gym (M)** Non-profit community gym. Positive Access Project for PLWHAs Mon, Wed, Fri 10am-1pm. At ACON, 9 Commonwealth St Surry Hills ☎ 9206 2000
 - **Pozwest (Western Sydney)** Support for heterosexual men and women and their partners. ☎ 1800 812 404 or the Haven ☎ 9672 3600
 - **The Haven (Western Sydney)** Social support, convalescent and respite care. Meals, massage, classes, cheap groceries + frozen goods, workshops, internet access. ☎ 9672 3600
 - **Blue Mountains PLWHA** Drop-in Centre 2 Station St, Katoomba. Peer support, meals. ☎ 4782 2119 ☺
 - **MacKillop Centre (Hunter)** Training + development. ☎ 4968 8788.
 - **Karumah (Newcastle)** Social + peer support for PLWHAs, carers, friends, family. Lunch Tue + Thu, monthly BBQ. ☎ 4940 8393 ☺
 - **Positive Support Network (Central Coast)** Support and referral services Mon-Fri 10am-3.30pm ☎ 4323 2905 ☐ posnet@telstra.easymail.com.au

infocus A caring carer

Since 1984, Community Support Network volunteers have supported NSW people living with HIV/AIDS independently in the community.

For the last 14 years, CSN volunteer Breda Drumgoole has been cooking, cleaning, shopping, walking dogs, facilitating support groups and marching in the CSN float for Mardi Gras.

At present Breda is a facilitator for new carers, but joined the organisation as a carer in 1989 after hearing a radio advertisement seeking volunteers.

"It is lovely the gratitude you get from the clients after doing a task that seem so easy to you but would take them hours. I am lucky that I have some spare time on my hands and am delighted that CSN is part of my life," Breda said.

"When I first started caring, I was surprised how dependent a client would be on me. How lonely they were and how the client could ring the office and someone was always willing to listen to their concerns," she said.

When asked what advice she would give to someone thinking about becoming a CSN carer, Breda responded: "Go for it, you meet some great people, you feel wonderful after doing a shift, the social side of CSN is great and I think if everyone volunteered a few hours of their time every two weeks imagine what a wonderful world we would have!"

— Nicola Addison

■ For further information on the services provided by CSN, or to find out about becoming a volunteer, call the numbers listed on this page.

- **Hepatitis C Council of NSW Hep C Helpline** ☎ 9332 1599 (NSW country 1800 803 990) ☐ www.hepatitisc.org.au

VICTORIA

- Area code (03)
- **People Living with HIV/AIDS Victoria (PLWHA Vic) (M) (V)** Advocacy, support, representation. Speakers' bureau, treatments officer, newsletter, events, social groups. 6 Claremont St South Yarra 3141 ☎ 9865 6772 ☐ www.plwhavictoria.org.au
 - **Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC) (M) (V)** 6 Claremont Street, South Yarra ☎ 9865 6700 ☐ www.vic aids.asn.au
 - **Positive Living Centre** Vibrant community centre and one-stop shop for services + activities for PLWHAs. Free tea/coffee/brunch, complementary therapies info/advice, massage, naturopathy, relaxation, yoga, low-cost meals, food pantry, emergency financial relief, peer support, youth program, legal centre, social/educational/self-development courses and activities, community support, outreach social work, computer/internet/training, fitness classes. 51 Commercial Road Prahran. ☎ 9865 6700 or 1800 134 840
 - **The Centre Clinic** Community health service for positive people and the LGBT community but open to all. Rear 77 Fitzroy Street St Kilda ☎ 9525 5866
 - **AIDS Housing Action Group** State-wide confidential housing service. ☎ 9417 4311 or 1800 674 311
 - **Positive Women Victoria (M)** Statewide peer support and advocacy group for women

- with HIV/AIDS. Confidential support, info, advice, publications. ☎ 9276 6918 ☐ www.positivewomen.org.au
- **Aidline (V)** Phone counselling, info, referrals. ☎ 9347 6099. HIV+ volunteers welcome, full training given. ☐ www.aidshep.org.au
 - **Straight Arrows (M)** Support, services for HIV+ heterosexuals and their families. ☎ 9276 3792 ☐ www.straightarrows.org.au
 - **Bouverie Centre** Free counselling for individuals, couples, friends or family infected or affected by HIV. ☎ 9376 9844 ☺
 - **Access Information Centre at the Alfred** Community resources on HIV, hepatitis and STDs, health research on the internet. ☎ 9276 6993
 - **Inform Victoria** Directory of services for PLWHAs ☐ www.inform.webcentral.com.au
 - **Country AIDS Network Victoria** ☎ 5443 8355 ☐ can@mail.hitech.net.au
 - **Hepatitis C Council of Victoria** ☎ 9380 4644 (Vic country 1800 703 003) ☐ www.hepcvic.org.au
 - **Hepatitis C Helpline (V)** Phone counselling, info, referral. ☎ 9349 1111. Hep C positive volunteers always welcome – full training given.



PHOTO: DONNA CAMPBELL

QUEENSLAND

- Area code (07)
- **Queensland Positive People (QPP) (M) (V)** Representing Queensland PLWHAs with offices in major centres around the state. 289 Vulture St, Woolloongabba ☎ 3013 5555 or 1800 177 434 ☐ www.quac.org.au/qpp
 - Brisbane (Allen Street Centre) ☎ 3846 3939
 - Cairns ☎ 4051 1028
 - Gold Coast ☎ 5576 8366
 - Sunshine Coast ☎ 5441 1222
 - Rockhampton ☎ 4938 7720
 - Mackay ☎ 4953 5071
 - Townsville ☎ 4721 1384
 - **Queensland AIDS Council (QuAC) (M) (V)** Education, advocacy, support. 187 Melbourne St, South Brisbane ☎ 3017 1777 ☐ www.quac.org.au
 - Cairns – Gay Education ☎ 4041 5451
 - Cairns – Indigenous Project ☎ 4035 6491
 - Gold Coast ☎ 5572 8739
 - Sunshine Coast ☎ 5452 9805
 - Townsville ☎ 4729 2263
 - **Hepatitis C Council of Qld (HCCQ) (M)** Education, support, info, advocacy, counselling. ☎ 3236 0610 or (Qld regions/country) 1800 648 491 ☐ www.hepatitisc.asn.au

SOUTH AUSTRALIA

- Area code (08)
- **PLWHA (SA) – Positive Living Centre (M) (V)** Positive Living Centre – community centre for PLWHA and those closely affected. Mental health counselling (men + women), treatment + other HIV info, medical/dental transport, legal advice, health + wellness

- activities (Friday lunches, community food store, etc), complementary therapies (massage, aromatherapy, spiritual healing), Positive Speakers Bureau, individual and sector advocacy. 16 Malwa Street Glandore ☎ 8293 3700 ☐ www.hivsa.org.au
- **AIDS Council of South Australia (ACSA) (M) (V)** Face-to-face and phone counselling, financial and practical assistance, individual advocacy. 64 Fullarton Rd Norwood ☎ 8334 1611 or 1800 888 559 ☐ www.acsa.org.au
 - **Adelaide Diocesan AIDS Centre 247** South Rd Mile End. Home care, counselling, intermediate accommodation, pastoral care, PAWS, lunch (Wed) ☎ 8234 9180
 - **HIV Women's Project** Peer support group, info, advocacy. 64 Pennington Tce North Adelaide ☐ info@whs.sa.gov.au ☎ 8239 9600 ☐ www.whs.sa.gov.au
 - **Mosaic Counselling** A confidential and free service for people affected by HIV or hepatitis C. ☎ 8245 8100 ☐ www.cope.edu.au
 - **Hepatitis C Council of SA** ☎ 8362 8443 (SA country 1800 021 133) ☐ www.hepcouncilsa.asn.au

WESTERN AUSTRALIA

- Area code (08)
- **HIV/AIDS Peer Advisory Network (HAPAN) (M)** PLWHA group, meets once a month. ☎ Cipri 9482 0000 ☐ hapan@wa aids.com
 - **WA AIDS Council (WAAC) (M) (V)** Support services, counselling, treatments info, complementary therapies (massage, Reiki, acupuncture and pranic healing), retreats, forums, workshops, one-to-one peer support, education, women's project, newly diagnosed program. 664 Murray St West Perth. ☎ 9482 0000 ☐ www.wa aids.com
 - **The Living Centre (HIV/AIDS Pastoral Care)** Peer, social and outreach support ☎ 9470 4931
 - **Spirituality Wellbeing and Support Group** ☎ Arpad 9247 1595 or Sabena 9482 0000
 - **Hepatitis Council of WA** ☎ 9227 9800 (general enquiries) 9328 8538 (support, info) 1800 800 070 (WA country) ☐ www.hepatitiswa.com.au

TASMANIA

- Area code (03)
- **Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCAHRD) (V)** 319 Liverpool St Hobart ☎ 6234 1242 or 1800 005 900 ☐ www.tascahrd.org.au
 - **Sexual Health Service** 60 Collins St Hobart ☎ 6233 8691

ACT

- Area code (02)
- **PLWHA/ACT (M) (V)** Social drop-in centre at the Rainbow Room, Westlind House. Free internet, holistic bodywork, positive speaker's bureau, women's group, financial assistance, social networks, advocacy, referral, support, counselling, info, dietician's clinic and workshops. 16 Gordon St Acton ☎ 6257 4985 ☐ plwha.act@aidsaction.org.au
 - **AIDS Action Council of the ACT (M) (V)** Information, referral and support. Westlind House, 16 Gordon Street, Acton ☎ 6257 2855 ☐ www.aidsaction.org.au
 - **Peer Support Network** Weekly social and educational night for positive people. Free dinner. Tue 6-8pm ☎ 6257 2855
 - **ACT Hepatitis C Council** ☎ 6253 9999 or HepLine 1300 301 383 ☐ www.acthepc.org

NORTHERN TERRITORY

- Area code (08)
- **PLWHA/NT (M)** PO Box 2826 Darwin 0801 ☎ Tony or Daniel 8941 1711
 - **NT AIDS and Hepatitis Council (NTAHC)** 46 Woods St Darwin 0800 ☎ 8941 1711 ☐ www.ntahc.org.au
 - Alice Springs ☎ 8953 3172
 - **Men's Line** Confidential phone support, info, referral for gay and bisexual men. Sun-Tue 5.30-10.30pm ☎ 8941 1711 or 1800 181 888
 - **Hep C Info Line** ☎ 8922 8007 or 1800 353 755

ARE YOUR DETAILS CORRECT? The Broadsheet lists services, programs and events of interest to HIV-positive people. To enquire about a free listing or to update your details, email: pl@napwa.org.au