Choosing a treatment regimen that will work after switching, swapping and changing drugs for many years can become quite a laborious and stressful task. Trying to pick drugs that still work can become a bit of guess work. However, Victorians should be able to breath a sigh of relief with new drugs now available to fill the gap. The fusion/entry inhibitor, T-20, has been available since the beginning of the year, but finding a new drug to use with it has not been easy. Fret not, the new protease inhibitor tipranavir is available via an access program for people with less than 150 CD4 cells (and this criteria may loosen very soon). Thus people with resistant virus now have access to 2 new drugs.

There are also new drugs available through clinical trials that are now recruiting in Melbourne. The new protease inhibitor, TMC 114, from Tibotec is available in a clinical trial. Clinical trial data have been more than promising, showing good results when T-20 is used with either TMC 114 or tipranavir. But wait….there is still more. There is also a new nucleoside analogue available in a clinical trial that works against resistant HIV called AVX 754. This new drug can be used as a substitute for 3TC in people who have been on a stable antiviral regimen for more than 2 months but who have not been able to achieve an undetectable viral load (2,000 to 20,000 copies/ml). Thus, for the first time in quite a while people with resistant virus have the opportunity to build up to a combination that contains 3 totally new drugs that could potentially stop the virus in its tracks. For more information on clinical trials in Melbourne please refer to the ‘Clinical Trials in Melbourne’ article later in this edition of Poslink.
Note from the Executive Officer
Sonny Williams

PLWHA Victoria held a Treatment Interactive Event on Sunday 21st August titled “Love, sex and the whole damn thing” compered by Vanessa Wagner @ Vibe on Smith Street Fitzroy.

Planet Positive @ Vibe 14th September had entertainment donated by Three Sisters. By having a social space for HIV Positive People and their friends, people can feel open about their status and feel safe in the knowledge that they are in an environment where being HIV Positive is the norm and not the exception. Remember that there is no charge for entry, a light snack in the way of finger food is served as well as your first free drink on arrival. If you have any suggestions or about what you would like to see at Planet Positive please email info @ plwhavictoria.org.au

As I have previously mentioned PLWHA Victoria are about to commence a Healthy Living Skills National pilot program covering aspects of diet, exercise and a quit smoking component. Suzy is currently conducting research for the project and will be calling for participants shortly; Suzy can be contacted on (03) 9865 6756. As a pilot project funded by the AFAO National Education Team (ANET) this program has the potential to be implemented on a national level, built into the program is a comprehensive evaluation process.

Alan Strum was away from the office for 6 weeks on vacation. Whilst away he married his beau of 11 years while in Canada. He has now returned to work and is available again for treatment enquiries on 9865 6718.

PLWHA Victoria’s Annual General Meeting

Positive Living Centre
51 Commercial Rd, Prahran

Sunday 27 November
1.30 pm

Join us for an annual review of the activities of People Living with HIV/AIDS Victoria. Election of board members, presentation of Annual Awards and acceptance of reports and financial statements. All welcome.

All members and supporters of PLWHA Victoria are encouraged to attend.
There has been a lot of discussion within our sector recently about the topic of HIV and Aging.

This is an area that has been given life thanks to the statistics coming out of the latest HIV Futures survey. One of the results of the survey was a recognition that the HIV positive population is (on aggregate) getting older.

This can be seen as a ‘good news’ issue, as the indications from these figures are that we, as a population, are living longer thanks the benefits of HAART.

This topic though is also a major challenge to both the sector and to the individuals within our community.

It raises a whole raft of new issues that we need to come to terms with. How will aging affect the HIV population; what complications will HIV add to the already known effects of aging on the immune system; what additional measures do we need to take to ensure adequate service provision to this population; what effect will aging and HIV have on our support structures and families; how can we, as a community, ensure that the older HIV positive population has a voice that is heard?

Like many in the HIV community sector, this topic is one that is very relevant to me personally, as I am one of the individuals that are on the cusp of becoming a member of this ‘older’ HIV population. I am turning 45 this weekend (all commiserations can be sent to the PLWHA office).

As someone who has been infected for over 20 years, I have lived through changes in my health and well-being thanks to this virus. But now I am at the stage of my life where you sometimes have to ask yourself ‘Are the changes that I am seeing due to HIV or are they just part of the normal process of aging?’ The answer largely is ‘I don’t know’. And it’s not only that I don’t know – a lot of the time, my doctors cannot give me a definitive answer and neither can my peers. We are all experiencing this for the first time. We are the generation that has got there first, and like all firsts, this is uncharted territory.

PLWHA Victoria’s next Treatment Interactive event intends to look at this area of HIV and Aging with the intention of sparking some discussion around this area. I would encourage our members to come along to this important forum, both to discuss avenues of research that can be done for this group and also to bring your stories on this topic to light.

(Please Note : This does not mean that the event is restricted to the older members of our group far from it!! We value the input and insight of all of our members, and young heads often come up with new ideas).

Another quick reminder that I would like to include in my report before closing is that the PLWHA Victoria AGM is fast approaching. I would like to put out the call again for any prospective board members to come forward. It looks as though we will have a few vacancies this year that need to be filled, with some long standing and hard working board members stepping down from their roles.

Remember that PLWHA can only be as strong as its members, and that for us to be an effective voice in the wider community, we need to ensure that we have a strong, capable and representative board that truly reflects the make-up of the positive population in Victoria. In these times of change - and it doesn’t look like it is going to be change for the better – we must keep a strong focus on our advocacy work, a keen eye on the issues that affect us and a web of links that spread throughout the positive community in our state and the country.
**What’s Up:**
**News and Information**

**Vaccine trial for anal wart virus**

A dose ranging and safety study for a new therapeutic vaccine is now underway at the Alfred called the AIN Study. The vaccine will ultimately be tested for efficacy against human papilloma viruses [HPV] (wart viruses) that are associated with cancerous changes in the anus. Treating cellular changes in the anus from HPV has not been an easy task for physicians. Sometimes the affected tissue needs to be removed to avoid the development of cancer. While this vaccine is not being tauted as a treatment for HPV it does offer people with precancerous tissue an opportunity to be involved in the development of a potentially active treatment for HPV and possible prevention of anal cancer. For more information on clinical trials in Melbourne please refer to the ‘Clinical Trials in Melbourne’ article later in this edition of Poslink.

**France leads the world for change**

The French President Jacques Chirac has announced that France will introduce a tax on airline tickets to help pay for the global fight against HIV/AIDS, malaria and TB. French officials have stated that the airline tax would cost no more than $6 per person travelling on international flights ($25 for business class travellers). In announcing this innovative move, Chirac is challenging leaders from 145 nations to follow his lead and introduce a similar tax in their countries. It is estimated that this tax would provide US $12 billion annually towards the global fund. [Editor’s note: Chirac should be praised for taking this action. In doing so he is the first world leader to say that it is the responsibility of every nation to actively fight diseases such as HIV, malaria and TB. Should Chirac’s tax be implemented on a world wide basis millions of lives will be saved].

**‘Sero-sorting’ reducing HIV in San Francisco?**

Health Officials in San Francisco have been baffled by a 50% reduction in new HIV cases among men who have sex with men over the last 4 years. While thought to be a reflection of a good testing campaign, it appears that gay men in San Francisco are taking advantage of internet sex by utilising matchmaking websites specifically built for HIV positive men. In doing so, HIV positive men are choosing sex partners who are also HIV positive.

**Valproic Acid – good news but not a cure**

Valproic acid is a drug used to treat bipolar disorder and epilepsy. Researchers appear have found a new use for it as a possible treatment for purging HIV from infected resting (dormant) immune cells. Valproic acid can signal HIV to replicate inside resting immune cells which then identifies them to the immune system to be killed (or they may die out after replication commences). It is the pool of infected resting immune cells that provides for ongoing infection in humans and prevents the possibility of a cure. In a recent study, 4 people who had been on treatment for 2 years at undetectable levels started T-20 6 weeks prior to taking valproic acid in order to protect new cells from HIV infection. Participants were then given the valproic acid for 16-18 weeks on top of their HIV drugs including T-20. At this time researchers observed a dramatic fall in infected resting cells of 68% to over 84% in three patients but only a reduction of 29% in one patient.

This is a proof of concept study only and shows that valproic acid can flush HIV out of some infected resting cells. There needs to be 100% eradication of infected resting cells in order for a potential cure to take place as only one resting infected cell is needed to start the infection process all over again. As 100% eradication of infected resting cells was not achieved, this cannot be viewed as a cure. However, it is a step in the right direction and a lot more research will be required.
Sex and Women
A recent study on sexual behaviour and relationships among 84 HIV positive women has shown that 60% of women experience sexual dysfunction. 59% of the women surveyed currently had a partner while 28% of women had not had a sexual partner since their diagnosis. The most prevalent sexual difficulties were infrequent sex (84%), avoidance (84%), non-communication (69%), and dysfunction (60%). 60% of women were experiencing significant levels of anxiety while 38% were depressed.

Love, sex and the whole damn thing!
In August PLWHA Victoria held the first treatment interactive event for 2005 called ‘Love, sex and the whole damn thing.’ The effervescent Vanessa Wagner was once again present to take us on a journey looking at having and building relationships for gay men with HIV. Our HIV positive presenters shared their lived experiences of relationships prior to having HIV and how the diagnosis affected their ability to have relationships. Afterwards peer support volunteer Vic Perri and relationships counsellor Kate Williams provided information to the audience focusing on specific topics that people wanted discussed.

PLWHA Victoria would like to thank our volunteers; Anna, Colin, De, Jason, Shane, Bernie, Ken, Greg and Tony, along with our expert panellists Kate and Vic for making the afternoon an informative and entertaining event.

December Treatment Interactive Event
PLWHA Victoria will be holding a Treatment Interactive Event in December called ‘Vanessa’s Christmas Nosh’ on Sunday 11 at Vibe Café and Bar. This event will provide information on new drugs and changes to HIV treatments that have occurred in the previous 12 months along with a festive atmosphere for the organisation and our members to celebrate the holiday season.

Alan gets married!
You may have noticed that our Treatments Information Officer, Alan Strum, has been out of the office lately. In fact, Alan was in Montreal taking advantage of the laws in Canada that allow same sex couples to marry. On October 8 Alan married his Canadian partner of 11 years, Philip, in a small ceremony with friends from Australia and Canada. Afterwards the happy grooms went to the Black and Blue Military Ball to celebrate with 1500 friends on the dance floor.
What’s Up: News and Information

All aboard the Garden Ship!

The Positive Plots Garden Ship is about to re-launched for another year and we are looking for 5 people to take over the garden plot at Veg Out Community Gardens in St Kilda.

Life is a garden. It’s what you put into it that will determine what you will get out of it. Positive Plots was developed as a pilot project in July 2004 to give HIV positive people in the City of Port Phillip the opportunity to form new social networks and contacts in a community garden space. The intention is to provide a safe local environment, to make new friends, with no costs involved for participants.

Last year, PLWHA Victoria negotiated a garden plot at St Kilda’s famous Veg Out community gardens to establish the Positive Plots initiative. In keeping with the location and its affinity with the sea, the plot is designed as a mythical pirate ship, complete with mast and rigging. The design accommodates those with disabilities by offering three different garden bed levels and incorporates a handy work bench and seat at the rear.

Public transport is close at hand and Veg-Out has excellent facilities which include kitchen, BBQ, tools, play areas, toilets and wash up facilities and even some animals.

Positive Plots has been running for a year to rave reviews from participants who have found the experience both rewarding and enriching. Participants have commented that the project has promoted self esteem, confidence and new social skills while decreasing feelings of isolation. For others, opportunities for new friends and contacts in a community garden space have decreased anxiety and promoted self worth.

Positive Plots is a hands-on activity and there is on the job coaching in gardening techniques. You don’t need to have a green thumb to take part in the project, all you need is a keen interest to get out and make new friends. If you like the idea of sharing a gardening plot to grow a abundance of vegetables, herbs and flowers then this is for you.

So if you want to get down and dirty in the garden patch and be a part of the pirate crew, if you enjoy the outdoors and playing with a few tools, then get aboard Positive Plots’ Pirate Ship.

If you would like to participate in Positive Plots contact Suzy at PLWHA Victoria on 9865 6756.
This is a second article on co-factors in HIV. Co-factors are things other than HIV that affect how you’ll go if you have HIV. Two issues ago we looked at the importance of an antioxidant called Glutathione as a co-factor. This issue the focus is on a human hormone called Dehydroepiandrosterone - or DHEA for short.

DHEA is a steroid hormone produced in the adrenal gland. It’s the most abundant steroid in the bloodstream and is present at even higher levels in brain tissue. DHEA is essential in the manufacture of many steroid sex hormones (including estrogen and testosterone). In men, around 50% of all testosterone is derived from it, while women derive over 75% of their estrogen from it.

DHEA levels are known to decrease with age, falling 90% from age 20 to age 90.

Interest in its importance in human functioning has been around since the 1960’s (1), however, serious studies of its relevance for people with HIV didn’t begin till the 1990’s.

One of the first important studies, conducted at the University of California, found that people with DHEA levels below the lower limit of normal (less than 180 ng/dl) were 2.34 times as likely to subsequently develop AIDS (p = .01). (2)

The researchers stated; “This is the first large prospective cohort in which an endocrinologic variable [DHEA] has been observed to independently predict progression to AIDS. These observations….. suggest that DHEA might have a protective effect in HIV infection.”

This predictive effect of low DHEA levels was confirmed a year later by research from the University of Amsterdam where low levels were again found to predict the development of AIDS (3).

This study concluded; “DHEA levels less than 7 nmol/l …….. proved to be [an] independent predictor for disease progression….”.

That is, low DHEA levels were a predictor of who was likely to develop AIDS, over and above the effect of low T4 counts.

However, these studies didn’t show that low DHEA actually caused the development of AIDS or that increasing DHEA levels would improve people’s health.

One of the first important trials of DHEA supplementation for people with HIV was presented at the 11th International AIDS Conference in 1996 (4). In this trial 20 people with HIV, all with T4 counts less than 242 and an average viral load of 112 000, took a DHEA supplement for 1 month. 17 of them had never taken any anti-HIV drugs and the other 3 had not taken any for at least 1 month. People took either 300mg or 600mg twice a day.

After 28 days the average viral load had fallen from 112 000 to 15 800. This is a reduction of 86% and a drop of log 0.85. There was no significant fall in viral load at the lower DHEA dose and there was no fall evident for either dose till after 14 days.

Generally, reduction in viral load did not begin until plasma levels of DHEA rose above 400mg/dl. [Note: plasma is the blood with all the cells taken out – Jim]. Unfortunately, this significant drop in viral load doesn’t seem typical for people with HIV taking oral DHEA.

Much more common is a reported increase in that crucial, but poorly defined, factor – “well-being”. This is often experienced as; more energy, better mood, better libido or more confidence etc.

The following study (see Table 1), among 29 women with HIV, shows this improvement in well-being after supplementation with DHEA (5).
16 women took 50mg DHEA every day for 6 months and were compared to 13 similar women taking placebo. All were on the same 3 anti-HIV drugs and had been for at least 10 months previously.

Note the overall improvement in a range of factors – ie the women reported feeling better, both physically and psychologically. Very interesting is the substantial rise in average T4 count.

This increase in T4 count has not been repeated in trials in men. One small trial closely followed nine HIV-negative older men (average age 63 years) who took 50mg of DHEA every night for 20 weeks (6). All of the men had low DHEA levels. They began the trial with a two week period on placebo. Compared to results on placebo the men had:

- No change in T cell numbers but T cell activity increased by 40% (p<.05).
- Natural killer cell (NK) numbers increased by 22-37% at 18 to 20 weeks (p<.01) and NK killing ability increased 45% by 18 to 20 weeks (p<.01).
- B cells numbers showed no clear change but B cell activity increased by 62% after 12 weeks (p<.05).

Clearly the DHEA had wide ranging effects on immune function. Note that some of these effects occurred quickly but others needed around 5 months of DHEA to appear.

Studies with larger numbers of participants and with better controls are needed to more completely understand the effects of DHEA on immunity. However, researchers concluded:

“While extended studies are required, our findings suggest potential therapeutic benefits of DHEA in immunodeficient states”.

A larger, placebo controlled, 4 month trial, (involving men with HIV this time), again found no increase in T4 counts. The average starting T4 counts of 33 were very low. However, there were marked improvements in what the researchers termed Mental Health (p = 0.001) and Health Distress (0.004) scores (7).

A more recent study has found very low levels of DHEA in people with co-infection with Hepatitis C (8). In a group of 137 people with HIV, thirty seven (27%) also had Hepatitis C. The average DHEA level for people with HIV only was 6.6 micromols/L, whereas people with co-infection had much lower levels of 2.1 (p<0.01)

**Use of DHEA Supplements**

If you are interested in following up this information here are some steps to take:

- First, get a doctor to check your blood levels of DHEA. DHEAs (DHEA sulphate) is probably the best form to measure.
- If your levels are in the optimum range (see below) then its unlikely that you’ll get any benefit from taking a DHEA supplement.
- However, if levels are below optimum then you can expect that supplementing with DHEA will be of benefit.
- There is a difference between the normal range and the optimum range. An American doctor, Dr Kaiser, who has prescribed DHEA extensively for his patients with HIV, recommends raising DHEA levels to optimum.
- He has found that the optimum DHEAs level for men is between 300 – 600 ug/dL and for women its between 100 – 300 ug/dL. Levels will

![TABLE 1: DHEA IMPROVES T4 COUNT, WEIGHT GAIN AND WELL-BEING. After 6 months using DHEA, women experienced the following statistically significant changes:](table.png)

<table>
<thead>
<tr>
<th></th>
<th>DHEA</th>
<th>PLACEBO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body weight (kg)</td>
<td>+ 1.36 kg</td>
<td>- 1.19kg</td>
</tr>
<tr>
<td>Change in energy (scale of 0-100)</td>
<td>+ 8</td>
<td>- 12</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>+ 10</td>
<td>- 18</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>+ 8</td>
<td>- 5</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>+ 8</td>
<td>- 7</td>
</tr>
<tr>
<td>Current health perception</td>
<td>+ 2</td>
<td>- 8</td>
</tr>
<tr>
<td>Change in T4’s</td>
<td>+ 107</td>
<td>- 11</td>
</tr>
</tbody>
</table>

![Complementary Therapies](image.png)

**DHEA**

**Co-Factors in HIV - No. 2**

*By Jim Arachne, Positive Living Centre*
be different if you measure DHEA versus DHEAs. Normal ranges may also vary between different pathology labs.

- For men, Dr Kaiser’s dosing recommendations are:
  - if levels are 200 – 300 ug/dL take 50mg 1/day
  - if levels are below 200 take 100mg 1/day
  - if levels are below 100 take 200mg 1/day

- For women if levels are below 100 take 25 - 50mg /day

**Safety of DHEA**

- DHEA is a human hormone so don’t assume its totally safe to supplement with – particularly over long periods. However, clinical trials have used very large amounts – over 2000 mg/day for at least 4 months – with no side effects seen. It’s been available “over-the-counter” in America for at least 20 years and is used by many people in Australia. A doctor’s prescription is required here. Discuss safety with your health care provider.

- Some anti-HIV drugs (especially Ritonavir but also possibly other protease inhibitors such as Indinavir and Saquinavir) will reduce breakdown of DHEA and lead to high blood levels. If you are taking Ritonavir or other PI cut the recomended dose by half. Note that Kaletra contains Ritonavir.

- Monitor DHEA levels regularly.

**Increasing DHEA Without Using Supplements**

Chronic stress will often deplete DHEA levels. The opposite is also true. That is, bringing more calm and peace into your life will usually raise DHEA. A trial of a 10 week “cognitive behavioural” stress management course successfully raised DHEA in a group of 43 men with HIV (9) – and was much cheaper than 10 weeks of supplements!

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**Complementary Therapies**

**DHEA**

**Co-Factors in HIV - No. 2**

*By Jim Arachne, Positive Living Centre*

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**Free Wills**

PLWHA Victoria offers members a limited* free will-making service via De Ayers.

For further information, please contact Frank on 9865 6772, and he will arrange for De to get in touch with you.

*Service covers up to six beneficiaries and no provision for setting up trusts, fund management or the like.
From my clinical observation of many people with HIV, I believe that some medicinal herbs can raise DHEA levels as well. However, little research has been done in this area.

[Editor’s note: It is illegal to import DHEA into Australia either in person or via the internet (I tried and got caught). It is possible to get an import license for a 3 month supply if your doctor agrees to fill in the paperwork. It is also possible to obtain DHEA with a doctors prescription from specialty pharmacies called compound pharmacies. There is at least one that I know of in Melbourne. A quick search on the internet should identify these pharmacies to you. While DHEA is very cheap in the USA, it can be quite expensive from compound pharmacies at around $55 per month for 50mg capsules]

References:


4. XI Int Conf AIDS, July 1996 Abstract Th B 4352


What’s going on at Positive Women
Mural Launch at Fairfield House
By Karen Allen

On September the 13th Positive Women (Victoria) Inc., Straight Arrows Inc. and The Alfred came together to launch the mural on the fence at Fairfield House. It was a well attended event and also a lot of fun. It was great to get together to celebrate something long lasting and beautiful in this sector rather than always concentrating on the virus. The launch was written up in QV and the Alfred newsletter. If you came along, thank you for attending, if you still haven’t seen the mural, well let’s just say we don’t think it will be going anywhere fast.

The end of the year is fast approaching, and we have many projects on the go. We will hopefully be launching the Positive Women’s pregnancy Resource at World AIDS Day.

We are also currently working on a pilot project which will offer much needed support to children of all HIV positive people, men, and women, gay or straight. We will be targeting young people in their adolescence and hope to run a support group that will in the end link the young people together to gain much needed peer support. So keep an eye out, we will be running Focus Groups before the end of the year and welcome parents and children. We will advertise the Focus Groups at the PLC and various other newsletters but we are looking at November the 21st as our first one, so put that in your diary if you are interested. We will expect for this type of support group that the kids are aware of your status as a positive parent.

Speaking of positive parents, I will be taking maternity leave from my position at Positive Women (Victoria) Inc. in February next year. I am expecting my first child, its all very exciting but makes me so aware as a positive woman of all the women who have gone before me, without their invaluable support and amazing stories I would be feeling very alone and even more confused. It makes me realize how important peer support is and reinforces what I do as a job everyday.

So, wish me luck and if you see an enormous heffalump wondering around at the PLC or around the traps…that’ll be me.

Till next time enjoy the sunny weather

Positive Women
Supporting Women Living with HIV/AIDS
Menstruation and pregnancy

If you are having irregular or problem periods, it may be difficult for you to become pregnant. If bleeding is occurring at irregular times it will be harder to monitor your menstrual cycle and to predict when ovulation (egg release) will occur. If you are trying to get pregnant check with your doctor that the irregularities you are having are normal, and will not interfere with a pregnancy.

Pregnancy

When women of child-bearing age are first told they are HIV positive it is very common for many to feel or be told they cannot or should not have children. This can cause great sadness and is incorrect. Due to the greater understanding of HIV, pregnancy and treatment options, many women in this situation are now considering starting a family or having more children.

If you are thinking about pregnancy

If you are pregnant or thinking about getting pregnant, you may want to talk to a doctor who knows how this can be managed in the safest way. It can also be helpful to talk to women with HIV who have been pregnant. Find a doctor who will support your decision. Your positive women’s group or your AIDS council can refer you to an experienced doctor or clinic. HIV can be transmitted from a positive woman to her child in three ways:

- during pregnancy;
- during labour and delivery;
- by breast-feeding.

A high viral load and a low CD4 count appear to be associated with the transmission of HIV.

Pregnancy, HIV and your health

There is no evidence that pregnancy leads to higher levels of virus or faster immune system damage, unless you are ill with AIDS-related conditions. When you are pregnant, your immune system is naturally under pressure, but your immune function should ‘bounce back’ after you have the baby. However, becoming pregnant when you are HIV positive may affect your health now or in the future. For instance, you may go on antiviral treatment when you are pregnant to reduce the risk of transmission to the baby. This may affect what treatments are available to you in the future. You might also want to consider having a caesarean delivery. This may be the safest way for the baby but it may not be the easiest for you as recovery from a Caesarean birth is more difficult than from a vaginal birth.

Talking over the options

If you are considering pregnancy, there are a number of things you may want to think about.

- If you have a partner, how do they feel about this?
- What is your CD4 count and viral load?
- If your CD4 count is low or your viral load high, do you need to consider antiviral treatment to reduce transmission risk to your child?
- How do you plan to become pregnant?
- What type of delivery (vaginal or Caesarean) would be best for you and your child?
- Do you feel well enough to cope with pregnancy or a newborn?
- What can you do to reduce the likelihood of your baby being born HIV positive?
- Do you understand the HIV testing regimen the baby will need to undergo for diagnosis?
- How will you manage feeding the baby?
- What ongoing support will you have when the child is born?
- Who would take care of the child if you became ill or were to die?

Having a child can be a joyful and tremendously rewarding experience for any woman. Having a child is also very tiring and can be a drain on your health and finances. A newborn baby is very demanding and older children also require considerable time and energy. If you are ill, it can be even harder to manage. Trying to manage work as well as caring for a child could place a heavy burden on your health. Adequate emotional and practical support, and financial security, will make a big difference to your ability to cope.

Getting pregnant

If you have a male partner who is HIV negative you may want to discuss ways of becoming pregnant that are acceptable to you both. Options include:

- unprotected penetrative sex at specific fertile times in your cycle (which is a small risk to your partner);
- your partner may consider starting post exposure prophylaxis (PEP) which could reduce the risk of transmission.
(this should be done in consultation with a doctor);
· inseminating yourself with semen ejaculated by your partner, called ‘self insemination’ (there are good books available on this technique);
· assisted insemination at a fertility clinic using your partner’s sperm or donated sperm. Fertility clinics are legally obliged to make their services available to anyone, regardless of HIV status, however some clinics may not be willing to assist you.

A supportive doctor can discuss the options with you. Information can also be found in women’s health centres or Family Planning clinics. If your partner is HIV positive and you have unprotected sex there is a theoretical risk that you will infect each other with a different strain of HIV. If you are concerned about this, there is a technique of ‘washing’ sperm which reduces the risk of HIV being transmitted. While this technique has been used in Italy for over a decade, and in some states of the USA, with successful results, it is not widely available in Australia. Detailed information on the procedure is available from the Family Planning Association of NSW, the ACON Women’s Project and the Reproductive Biology Unit at the Royal Women’s Hospital, Melbourne.

Unplanned pregnancy
If your pregnancy is unplanned you may face some very difficult decisions, including whether to continue with the pregnancy or have a termination (abortion). For some positive women an unplanned pregnancy has been a gift, and resulted in a healthy, negative child. For other women, it has been an enormous trauma as they grapple with conflicting emotions about the pregnancy. It is your right to decide whether to continue with the pregnancy or to have a termination. Pregnancy counselling is available in all states and territories through abortion clinics, women’s hospitals, Family Planning clinics, and GPs. However, you may also need to seek expert advice about HIV and pregnancy to help you decide. If you decide not to continue, you need to discuss this decision with a doctor as soon as possible — ideally within the first four to six weeks of your pregnancy. Most terminations are preformed at a clinic or hospital between seven and twelve weeks after the first day of your last period. If you decide to continue with the pregnancy, talk to your doctor as soon as possible about how you can reduce the risk of transmitting HIV to your baby.

Reducing the risk of transmission
The risk of transmitting HIV to your child is very low (under three percent) if:
· your viral load is low or undetectable;
· your CD4 count is high;
· you use antivirals during pregnancy and delivery to reduce your viral load;
· you have a Caesarean birth;
· you have access to good obstetric care;
· you do not breast feed.

If you are not very well, discuss with your doctor how your pregnancy and labour might be made safer for you and the baby.

How is pregnancy managed in women with HIV?
Find out if your doctor knows how pregnancy is managed when a woman is HIV positive. It is a good idea to see an HIV-experienced obstetrician early in your pregnancy if possible. Ask your positive women’s group or AIDS Council for a referral. As well as all the usual health checks recommended during pregnancy, it is a good idea to closely monitor your HIV. This may include CD4 cell counts, viral load and liver function tests, and glucose levels, among others.

Using antivirals
In Australia, many HIV positive women have now had HIV negative babies. Combination therapies have dramatically improved the outlook for positive women wanting to have a child. If you are not currently taking antivirals, you may be advised to consider doing so, in order to reduce the risk of transmitting HIV to the baby. A combination of three drugs, from at least two different classes, remains standard of care for adults. While women who are pregnant are generally recommended to continue or start antiviral treatments it is best to discuss your options with your doctor. You and your doctor can decide on the best therapy regime after considering a range of factors including: how far your pregnancy is advanced; your antiviral treatment history; and your CD4 and viral load counts.

We know relatively little about what role most antivirals have in preventing mother-to-child transmission, however exciting information about nevirapine has recently been released. Early results from a joint US-Uganda study show that a single oral dose of nevirapine given to a woman in labor, and another to her baby within three days of birth, reduces the transmission rate by half compared to a similar short course of AZT. At 14 to 16 weeks
of age, 13.1 percent of infants who received nevirapine were HIV positive, compared with 25.1 percent of those in the AZT arm of the study. Long-term follow-up of both the mothers and their babies will show if there are any adverse side effects to this treatment. AZT remains the most researched drug in this area. It has been conclusively shown to reduce the risk of babies being born HIV positive. In resource-poor countries where antiviral use is not widespread, AZT is sometimes used alone, from 14 or even 36 weeks into the pregnancy, to lower the transmission risk. Using AZT by itself can pose health risks for the mother. AZT monotherapy is not considered an acceptable standard of care for adults.

If you are considering taking antivirals during pregnancy you are likely to be offered a combination which contains AZT. However, if your current antiviral treatment is effective and does not include AZT it is likely you will be advised to remain on that combination, unless there are some concerns about the possible effect of some of these drugs on the foetus. Although little research has been conducted, some antiviral drugs are potentially damaging to the unborn child. Zalcitabine (ddC) is one of these. The experimental drug efavirenz, which is available in Australia through a special access scheme, has been linked to birth defects in animals. It should not be used in pregnancy. Ask your doctor or obstetrician to help you find out the latest information about other antivirals in pregnancy.

Managing pregnancy without antivirals
You may be under considerable pressure to use antivirals during your pregnancy. But what if you don’t wish to? The strongest risk factor for a baby being born positive is the mother’s viral load. If your viral load is low and your CD4 count is high, you may not want to begin any treatment. It is your decision, and you do have the right not to take antivirals or other medications during your pregnancy. Many healthy HIV-negative babies have now been born to women on combination antiviral therapy, but because the drugs are relatively new, the effects of many anti-HIV drugs during pregnancy and on unborn children are poorly understood. There is little data on any long-term effects on babies or children, and of course there is no data on how their children may be affected, if at all. If you do choose not to use antiviral drugs, it is extremely important to keep a close eye on your health during the pregnancy. You may need to monitor for any changes to your viral load and CD4 count more often.

Delivery
You and your doctor should discuss the possibility of a planned Caesarean delivery — also known as an ‘elective Caesarean’. Studies have now clearly shown that the risk of transmission is halved if the baby is delivered by a Caesarean section, in conjunction with antiviral therapy during pregnancy and avoiding breastfeeding. If you have a vaginal delivery, your doctor may want to limit the time you spend in labour. Studies have shown that babies are less likely to be infected if the labour is no longer than four hours after the membranes have ruptured (waters broken). Doctors and others involved with the delivery should also avoid the use of instruments like forceps and foetal scalp electrodes, which may break skin or membrane and increase risk of transmission.

What about the baby?
The current management of newborn babies of HIV positive women includes oral AZT within 24 hours of birth, to be continued every six hours for six weeks as a prophylactic measure. On its own, this has been found to significantly reduce HIV infection in infants. Although it is too soon to be certain about long-term effects, babies born so far to mothers who have taken AZT have shown no side effects. There does not appear to be increased risk of birth defects or growth problems in infants. It is still a difficult decision for a mother to subject a newborn baby to a rigid drug regimen. Make sure you are fully informed about any such treatments and have made your decision about any treatments before the birth. Due to the time delays in diagnosing whether a newborn baby is infected with HIV, your baby may also be given medicine to protect against chest infection and pneumonia as a precautionary measure.

How Do I Know If My Baby Is Positive?
In the past one of the hardest things for HIV positive mothers was not knowing their baby’s HIV status until the child was 18 months old. It is important to note that all babies are born with
antibodies that their mother carries, be it HIV or antibodies to the common cold. Carrying the antibodies does not mean the baby will be infected with HIV. To check if the baby is infected with HIV he or she will have to undergo a simple blood test known as a PCR test. This test is carried out after birth and at regular intervals up to 18 months of age — the tests look for the presence of HIV itself. Current guidelines recommend that PCR tests be carried out with 24 - 48 hours of birth, at ages one week, six weeks, three months, six months and twelve months. If all the tests return negative in the first three months it is extremely likely that your baby is not infected with HIV. You can feel further reassured when your baby is tested again up to 18 months of age as it will confirm that your antibodies have gone.

**What if my baby is positive?**
If your baby is HIV positive, the paediatrician will suggest you start your baby on antiviral treatment immediately. Your baby’s health will be closely monitored. Although babies and children do not respond as well to antiviral treatment as do adults, the treatment is improving all the time. You do have the right to refuse antiviral treatment for your child. Many children with HIV are now living happy, healthy lives. There are specialist HIV paediatricians around Australia, but especially in Sydney and Melbourne, who will be able to advise you and your doctor about the latest treatments.

**Breast Feeding**
Research indicates that breast feeding significantly increases the risk of HIV transmission from mother to child. In a policy statement on infant feeding, the World Health Organisation stated that world wide, one third of HIV positive infants are infected through breastfeeding. In Australia and other developed countries, where it is usually easy to maintain high levels of hygiene around bottle feeding, it is recommended not to breast feed. Some women may be concerned about the nutritional value of formula and therefore consider expressing milk and boiling it for the baby. While boiled expressed milk is safe to feed the baby, the boiling process destroys many of the valuable properties of breast milk. As a result, most women opt to bottle feed their babies using a breast milk substitute.

If both the first and the second PCR test after birth return positive, it is likely that your baby has been infected with HIV. If this occurs you might wish to consider breastfeeding. It is probably best to talk the issues through with your doctor before going ahead with any decision. Lactation consultants, available at most maternity hospitals, can help you establish breastfeeding.

HIV positive women have expressed feelings of relief that bottle feeding reduces the overall risk of HIV transmission. However many women have a strong desire to breast feed and you may experience feelings of loss and grief if you choose not to breastfeed your baby, which it is important to acknowledge.

While many women feel that breastfeeding plays an important role in bonding with their newborn, there are many other ways of satisfying the emotional needs which breastfeeding usually meets, such as massaging your baby, or skin-to-skin contact while you bottle feed. Sometimes health care workers and new mothers’ groups discuss issues around breast feeding. If you don’t wish to disclose your HIV status outside of a close circle of family and friends you may want to consider how you might deal with this situation. It is important to have made firm decisions about whether or not you will breastfeed your baby well before the birth. Ensuring that vital support is in place from early in your pregnancy can reduce your anxiety and help you work out your options.
Alan Strum interviews Brian Price and Mark Beltchev about services offered by the Alfred Hospital and Fairfield House for HIV positive Victorians - how things have changed over the years and what people can expect when they stay at Fairfield House or the Hospital.

Alan Strum (AS): Tell me what your roles are at the Alfred and Fairfield House?

Brian Price (BP): I work within the infectious diseases unit as the business and community services manager. In a way I provide the link between the HIV services and the community.

Mark Beltchev (MB): I am the nurse unit manager at Fairfield House.

AS: Can you describe the services available to people at the Alfred Hospital and Fairfield House?

BP: We offer a comprehensive range of services for PLWHA. From traditional hospital services such as acute care provided in 7 West and non-acute or sub acute services in Fairfield House. We also have a range of ambulatory services from out patients to day care and then a range of public health services such as the Access Information Centre, the Multicultural Health and Support Service, we have Berry Street which offers supportive accommodation, respite and emergency accommodation through to a clinical research unit and allied health services such as counselling, physiotherapy and exercise classes, nutrition, occupational therapy and the Victorian HIV Consultancy that does rural outreach and support work for complex care management.

AS: Can you talk a bit about the differences between acute care, sub-acute care and respite care?

MB: Acute care is when people are relatively unwell and need a lot of medical investigations. Sub-acute care is when people are starting to feel better and are healing. Respite is where someone is being cared for at home when they can’t look after themselves. They come in either to give themselves a break from home or to give their carers a break from caring for them.

BP: Social respite is where somebody is medically stable and they need to come in for a break which may relate to escaping their environment where they need time out. What we’ve traditionally called respite care over the years is quite broad and we are looking to slowly change the terminology to better describe what people come into Fairfield House for because we used to describe most people coming in as respite care. In reality they are often coming in for a number of investigations and follow up done for their medical management for what was often their chronic illness management. So for this group we are trying to better define this by saying that people are coming in for what we are calling ‘health maintenance’ rather than respite because they aren’t just coming in for a break but are usually coming in
for a number of health issues to be sorted out that are related to living with HIV as chronic illness which often involves a number of health issues. So we are now trying to define social respite as a person who needs a break from their social environment, their family or their carer.

**AS:** Tell me a bit about 7-West and what people can expect if they stay there?

**MB:** 7-West is the acute care HIV and infectious diseases ward. People who are acutely unwell who require a lot of medical investigations, medical reviews to find out what is wrong with them and to ultimately get their health stabilised. People in 7-West are closely monitored throughout their stay. This may also involve a number of specialists assisting in their health problems.

**AS:** Tell me a bit about Fairfield House and what people can expect if they stay there?

**MB:** Fairfield House is a sub-acute 15 bed unit. People are admitted for a whole variety of reasons. They may be transferred down from 7-West for further investigations and recuperation to make sure everything has stabilised. It can be for looking at antiretroviral related issues like starting treatment or dealing with toxicities, issues around co-infection with Hep B or Hep C, mild psychiatric conditions, non-problematic drug and alcohol issues, investigations into cognitive functions and cognitive decline, end of life care or respite. So people come in for quite a range of reasons.

**AS:** Where 7-West offers very close monitoring for acute illnesses, how much monitoring takes place in Fairfield House?

**MB:** We still have the same number of nurses per patient ratio so monitoring is still quite close. On a morning shift there’ll be one nurse to four patients but you have to remember that our patients are nowhere as acutely unwell as those in 7-West. Patients are still able to get over to the main hospital for investigations such as X-rays. We have a doctor on permanently on ward so there is still quite close monitoring and observation from both the medical and nursing perspective. We also have all the ancillary services there such as physiotherapists, social workers, dieticians and occupational therapists.

**BP:** It’s likely the level of medical and nursing intervention at Fairfield House is less complex than in 7-West.

**AS:** Could you take me through what you think an average daily routine would be for someone staying in Fairfield House?

**MB:** There is no real average daily routine because people are staying for such individual reasons. Someone might stay in bed till 11am and do nothing all day where as someone else may have a medical review in the morning or may have a surgical procedure that they have to be prepared for and be transported to the main hospital, they may have gym or maybe physiotherapy session. However, breakfast is at 8am.

**PB:** You’d expect to see a doctor everyday and you’d have the nurses popping in throughout the day as well. Some people staying for social respite don’t want that but when you stay in a hospital there is a need for a medical assessment and a level of ongoing monitoring to ensure the service has an understanding of where health is at as we have a duty of care relating to your health care.

**AS:** If a person is thinking about staying at Fairfield House do they have to stay there the whole time or are they encouraged to get out and do other things?

**MB:** It depends what that person has come in for. If someone is experiencing a problem and we are doing investigations then we will inform them when all there investigations are taking place. Certainly the freedom is there for them to come and go and we encourage people to go to the Access Information Centre or to the PLC. But it can get a bit difficult at times when doctors are doing rounds and the patients aren’t there because they are out of the building.

**BP:** If people are staying for an extended period there has never been an issue with people going home for the weekend or overnight as long as the staff have an understanding of what is going on and as long as the leave
doesn’t interfere with there treatment.

AS: Have there been any changes recently and does Fairfield House operate differently today than how it operated it previous years.

PB: The main changes have been in the disease and the presentations. Previously we had a large number of people who were palliative which meant people used to stay for longer periods of time and shared care arrangements with community carers, RDNS and their GP. So now that we have less people actually dying the service has needed to go through an adjustment and education process for the staff and the service to adapt to the changes in care needs for PLWHA. Fairfield House was originally designed to be a palliative care service with a high level of skill and training in the team focused on palliative care. We had 10 HIV beds and 5 general palliative care beds. About two years ago we also changed that model to provide 15 beds for HIV care because we accepted that the palliative care expertise was now rarely required with the main requirement now and we are moving more towards expertise in drug and alcohol management, psychiatric care, behaviour management in addition to general HIV care management.

MB: I think the other big changes is that Fairfield House is becoming better known for management of longer term antiretroviral management involving responding to side effects, commencement of treatment, changes in treatment and treatment reviews.

BP: More broadly there has been a change in demand for the acute hospital beds and we looking at how we can redirect services to meet new emerging needs which there will there will be community consultation about in the near future.

AS: Do you think people sometimes get the wrong idea of the service Fairfield House offers and why do you think this is?

MB: There seems to be a perception in the broader community that Fairfield House is still a palliative care service based on the history behind the service. There was a lot less social respite care back then. It certainly has changed since then and it is taking time to change that perception.

PB: I certainly think that part of what we are doing now is getting out and starting to articulate more about is the broad reasons people are being admitted to Fairfield House and what services we have to offer. We need to be better at communicating about what Fairfield House offers and the high quality care services that it provides.

AS: So who can be admitted to Fairfield House and what are the admission procedures?

MB: Basically anyone who is HIV positive can be admitted to Fairfield House. There are several avenues of admission either through general practitioners, the Royal District Nursing Service, or simply by contacting myself or my delegates at Fairfield House. You can also get admitted through the Accident and Emergency unit if you are feeling unwell.

BP: Our aim is to get a good understanding of what the individual persons needs are. Because it’s a sub-acute service environment we expect that people are not coming with acute illness and hence they don’t need to be hospitalised that day. Our aim is to have a good understanding of there needs which may require discussions with their health provider and discuss what they want to get out of the stay at Fairfield House. So then we can plan around that as well and that the patient and the service have the same expectation of their stay.

MB: One of the models we are looking at now is what we are calling health maintenance where someone may be booked into Fairfield House for three or four days every six months or so for a review of their medication and with all the ambulatory health services. We are trying to make sure that everything is tweaked and that they stay healthy.

AS: Are people ever refused admission to Fairfield House and why?

MB: The two groups of people who are refused admission to Fairfield House are those who are acutely unwell who need a
lot more monitoring and services than we can offer. This group would go to 7-West or another ward depending on their illness or someone who is acutely psychiatrically unwell or someone going through severe drug and alcohol withdrawals where Fairfield House is not the appropriate safe place for them these individuals would be referred to other more appropriate health services. Once the acute phase settles down then they can come to Fairfield House.

**AS:** If I wanted to be admitted to Fairfield House tomorrow, would I be able to get in?

**MB:** Today you would! But sometimes we are full and have several people on a waiting list so the priority is triaged. So your need may be less than someone else’s. That’s why we have the referral form so we can have as much information as possible to determine who has the greatest care need for the bed.

**BP:** Demand for the beds does fluctuate. At the moment we have some free beds but we didn’t have free beds three weeks ago and had a large waiting list. There are a number of things that have to be balanced and juggled around sometimes. However, if someone is acutely unwell we are able to facilitate them getting into 7-West if they need immediate medical treatment. When we have to delay an admission there is always discussion with the individual and they usually get in within a one or two days.

**AS:** At PLWHA Victoria we consider that Fairfield House offers an excellent service and that we are very lucky to have this service in Victoria. Can you tell me one thing you really like about Fairfield House and one thing you think can be improved?

**MB:** The service is well known and regarded across HIV services within Australia and offers a range of services other states don’t have. I really like the staff that we have there who are all very caring and committed. Our facility is second to none. We need to have further discussion and work with the community around ‘respite’ needs and ensure that between Fairfield House and now with Berry Street fully up and running that we determine what needs are being missed and how collectively we address those with the community.

**BP:** I think we need to get better at talking with the community about what is happening at Fairfield House about the types of patients and the care needs that they require. The real emerging needs around mental health, complex care issues, behavioural issues and drug and alcohol issues is going to be a real challenge for the community. I think HIV is a challenging area to work in and I think the staff are committed to working in this area and are constantly updating their skills to deal with new emerging issues associated with HIV.

We are about to turn 5 years old and we will be having a celebration in November so we will be welcoming anyone who has stayed in Fairfield House to come along and celebrate with us.

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**Fairfield House 5th Birthday Celebration**

Invitation: The Statewide HIV/AIDS Service at The Alfred would like to invite patients of the HIV service to join us in celebrating the significant contribution Fairfield House has made to people living with HIV/AIDS. Come and join us for lunch.

**SPIT ROAST LUNCH**

Sunday 13th November 12 noon - 2:30pm

A ticket is required for catering purposes: Please contact the Ward Clerk at Fairfield House for a ticket on 9276 2700 or email: HIV@alfred.org.au
This was my second ASHM (Australasian Society of HIV Medicine) Conference, and the two could not have been any more different – apart from the obvious location difference….last year being in Canberra and this one hitting Hobart.

From the opening plenary – where NAPWA President, Gabe McCarthy, reminded people of Tasmania’s significance in the formulation of PLWHA Organisations, I knew I was in for a very different “medical” conference. By this I mean the “community” content!

Congratulations to the organisers for this. Even the overseas guest speakers (in the main) had some sort of community content included in their presentations – possibly the medical fraternity is finally understanding that People Living with HIV/AIDS and the organisations with the responsibility for advocacy and education of same DO have a role to play in the ongoing maintenance of the pandemic. I must add that the majority of the community content was presented by NAPWA – but this also highlights the good working relationship the two “ends” of the spectrum have come to enjoy.

Many subjects were covered (as you could imagine at a four day conference) including:

· The difference in language used between patients and Doctors
· The obvious need for further development of drugs to fight HIV – as PLWHA live longer, resistance has grown accordingly
· Major research work being done overseas both for HIV and HIV/Hep C co-infected people
· The clear (and welcomed) role People Living with HIV/AIDS are increasingly playing in the education and prevention areas of the sector
· The invaluable role researchers are playing both in the education and Political arenas

Although a lot of the heavier medical sessions escaped my understanding (I am clearly NOT a Doctor or researcher), most of the speakers attempted to make their presentation as easy to understand as possible.

I personally thank the Department of Health Services (DHS) in Victoria for allowing me the opportunity by funding the trip (through a special grant scheme) and PLWHA (Vic) for allowing me to represent the organisation.

My thoughts about Tasmania – or at least Hobart – will wait for a follow up report…..although I must say the Whisky I bought from the Lark Distillery is going down very well.

Brett Hayhoe
Secretary PLWHA (Vic)
Victorian State Representative – NAPWA
Secretary AHAG
Member of Alfred Hospital HIV/AIDS Care Committee
Member of DWF Committee
Member Rep. PLC Advisory Committee

Our Place, Your Place...
...in the bigger picture

NAPWA 2005 Secretariat, LMB 5657 Darlinghurst NSW 1300 • 02 8254 0778 • conferences@napwa.org.au • www.napwa.org.au

10th National Conference of People Living with HIV/AIDS Adelaide, South Australia • 18–20 November 2005
HIV clinical trials in Melbourne

The following information relates to a number of studies that are currently enrolling in Melbourne at various clinics around the city. The information is only a brief outline of the studies and further information including inclusion and exclusion criteria are available by calling the clinical trial nurses at the locations on the numbers provided. Please keep in mind that a number of studies are currently being approved through ethics committees and cannot be listed here until they are approved. Thus it is recommended that you talk with your doctor or the clinical trial nurse at your medical centre to see whether any new studies have opened that you might be interested in. As such not every study is listed in Table 1 below.

You can also call the PLWHA Victoria Treatments Information Officer, Alan Strum, on 9865 6718 for more detailed information about the studies including some of the pros and cons of being in a clinical trial.

Trials currently enrolling

Teddi Study
This is an adherence study investigating the benefits of taking a once daily combination of drugs versus a twice daily combination of drugs. All participants will be offered the option of switching to a once daily combination after 24 weeks.

Study sites: MSHC

SMART
A study investigating the differences between starting and stopping treatment versus staying on treatment without breaks. Entry requires a CD4 count above 350 and a willingness to take treatment breaks or to stay on treatment without a break.

Study sites: Alfred, PMC, Centre Clinic, Northcote Clinic, Carlton Clinic, MSHC.

PHAEDRA
An observational study of people with early or acute HIV infection. Investigators are currently focusing on people who are not treating HIV in the acute stage. However the choice to start treatment is at the discretion of the doctor and the patient.

Study sites: Alfred, PMC, Centre Clinic, Northcote Clinic, Carlton Clinic, MSHC.

Tenofovir in HBV/HIV co-infection
A study investigating the affects of tenofovir (an anti-HIV drug) on Hepatitis B in people with HIV and Hepatitis B.

Study sites: Alfred

Cellular immune responses to Hepatitis B
A study investigating why some people clear Hepatitis B and others don’t in people with and without HIV. This study is open to people with HIV who are about to start treatment for Hepatitis B.

Study sites: Alfred and Royal Melbourne Hospital.

Liver disease with HIV and Hepatitis B co-infection
An observational study investigating the affects of chronic Hepatitis B in people with HIV taking anti-HIV combination therapy.

Study sites: Alfred and Royal Melbourne Hospital.

Fish Oil Trial
A randomised study investigating the affects of Fish Oil on the high triglycerides caused by HIV medications. The aim is to reduce the triglyceride levels.

Study sites: Alfred

Table 1: Contact Numbers and sites for clinical trials

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<thead>
<tr>
<th>Location</th>
<th>Phone number</th>
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<tbody>
<tr>
<td>The Alfred</td>
<td>9276 6908</td>
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<tr>
<td>Carlton Clinic</td>
<td>9347 9422</td>
</tr>
<tr>
<td>MSHC</td>
<td>9347 4144</td>
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<tr>
<td>Prahan Market Clinic</td>
<td>9826 4500</td>
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<tr>
<td>Centre Clinic</td>
<td>9525 5866</td>
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<tr>
<td>Northcote Clinic</td>
<td>9481 7155</td>
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AIN vaccine study
An early phase dose ranging study testing the safety and tolerability of a therapeutic vaccine developed to treat Human Papilloma Virus (specific types of wart virus) where the virus identified is known to cause cancerous tissue changes in the anus in people with HIV. People with uncontroled disease or diagnosis of malignancy are excluded.

Study sites: Alfred

Pfizer CCR5 inhibitor study
A study investigating the efficacy of the Pfizer CCR5 inhibitor drug called Maraviroc in people with HIV who have never taken HIV drugs previously in people who have previously taken HIV drugs who only have CCR5 tropic virus (studies 1026 and 1028). [CCR5 inhibitors may cause an increase in or change CCR5 virus to CXCR4 virus that could speed up disease progression. Feel free to call me on 9865 6718 if you need this explained to you prior to entering into the study. The study is designed to look at this aspect of viral replication and disease process.]

Study sites: Alfred, PMC, Carlton Clinic.

Reverse Cholesterol Transport
A study investigating the effects of HIV infection and HIV drug therapies on cholesterol (fat molecules in the blood) and the reverse cholesterol transport mechanism. The study is open to people who have never taken anti-HIV drugs previously, people who are about to take a protease inhibitor for the first time, and people who have never taken anti-HIV drugs previously and who are about to start treatment with a combination containing an NNRTI like efavirenz or nevirapine.

Study sites: Alfred, PMC, Centre Clinic, Northcote Clinic, Carlton Clinic

Naïve T-cell Study
This study investigates the role of HIV infection in new (naïve) T-cells (CD4s) and the effect this has on the decline of the CD4 count in people with a CD4 count greater than 300 and a viral load greater than 2000.

Study sites: Alfred.

Drug Hypersensitivity Study
This study will investigate immune and genetic factors that lead to allergic reactions to abacavir, nevirapine or efavirenz in people who have had a reaction to these drugs. People who have not had a reaction to these drugs are also needed to enrol in this study as controls (a reference point of what is normal).

Study sites: PMC only

GSK CCR5 inhibitor screening study*
This is a pre-recruitment phase to assess a persons eligibility for different arms/studies of the GSK CCR5 inhibitor GW873140. CCR5 inhibitors prevent HIV entering into cells in people with CCR5 [tropic] virus. The drug component of the study is not yet open for recruitment but this process should speed up access to the study once it has opened. [CCR5 inhibitors may cause an increase in or switch to CXCR4 virus that could speed up disease progression. Feel free to call me on 9865 6718 if you need this explained to you prior to entering into the study. The study is designed to look at this aspect of viral replication and disease process.]

Study sites: Alfred, PMC, Carlton Clinic and Royal Melbourne Hospital.

*NB – new information: GSK have released information advising that studies with this compound will only be in treatment experienced patients.

GSK protease inhibitor - HPR20001
A phase II dose ranging study of a new protease inhibitor with activity against resistant HIV. People need to have protease inhibitor resistance with 2 or more protease inhibitor mutations (codons) and a viral load greater than 1000 copies.

Study sites: PMC only

Treatments Update: what’s new, what’s changed

This year's ASHM conference showed just how much Australian doctors have matured in their approach to HIV medicine. A consensus forum was held on the last day for the development of guidelines for HIV therapy based on clinical trial data. As such, much of the information presented at the conference was geared towards the foundations for the antiviral guidelines. I was slightly disappointed in the clinical stream as very little new information seemed to be forthcoming. However, this is more a reflection that Poslink has been keeping us up to date rather than a lack of information being presented. There were a few golden gems of information that are shown below.

New definition for salvage therapy.
In an excellent overview for management of virological failure to antivirals, Prof. David Cooper from Sydney presented data showing good results when the entry inhibitor T-20 (Fuzeon) is used with new protease inhibitors such as tipranavir or TMC 114. Both of these protease inhibitors show activity against resistant forms of HIV. When either of these protease inhibitors are used with an optimal background therapy and T-20, around 65% of people with resistant virus can achieve an undetectable viral load that is sustained over time. Thus, where salvage therapy used to be used as a term in most people after using two rounds of treatment combinations resulting in virological failure, now salvage therapy refers to treatment following use with T-20 and tipranavir or TMC 114 (see table 1). Tipranavir is currently available through a patient access program for people with less than 150 CD4 cells while TMC 114 is available through clinical trials.

Innovative vaccine
Steven Kent from Melbourne presented his research on an innovative approach to vaccines. In order for vaccines to effectively fight HIV they need to induce a strong cellular immune response to HIV. In the new model presented, Steven Kent took whole blood (red blood cells) from monkeys and coated them with lots of small pieces of HIV proteins (peptides) and placed the treated blood back into the monkeys. When this technique was repeated 3 times the monkeys showed a remarkable cellular (CD4 and CD8) immune response to HIV. It is postulated that this approach may provide for an effective therapeutic and/or prophylactic vaccine against HIV in humans. Steven also put forward an hypothesis that while it might be difficult to change the course of HIV disease with vaccines to reduce viral loads, it may be possible to produce a vaccine to stimulate the immune system to recognise and abolish drug resistant forms of HIV, thereby trapping the virus into remaining sensitive to current drug therapies. [Editor's note: This is quite exciting work that Steven is doing. The technique he is developing appears to be quite a simple process that should be able to be used even in resource limited settings. I look forward to watching this research develop.]

L-acetyl carnitine and nerve cells
Dr Kate Cherry from Melbourne presented data on a test tube study looking at using the nutrient supplement L-acetyl carnitine (LAC) to prevent damage to nerve cells from HIV drugs like d4T. It is thought that
the nerve cell damage is due to reduced energy output from the mitochondria (energy factories) inside the cells. LAC has been used for many years by plwha to alleviate pain associated with peripheral neuropathy (burning or tingling in the hands or feet) that can be caused either by HIV or some HIV drugs. Some studies have shown benefit of using LAC for peripheral neuropathy but results have been a little mixed and the effective dose has never really been determined. Dr Cherry’s data clearly showed that LAC protected nerve cells from damage associated with nucleoside analogues (d4T) and hopes to do more research in this area. [Editor’s note: LAC is available from the PLC vitamin service. The current dose is considered to be 1500mg twice daily which can be quite expensive. One study from the UK has shown benefit for people with peripheral neuropathy but the pain returns when the LAC is stopped.]

When to treat Hepatitis C?
Francesca Torriani from San Francisco presented some thoughts on when might be the best time to treat Hepatitis C (HCV) in people co-infected with HIV (please be aware that treatment is restricted to strict criteria in Australia for access to anti-HCV therapy and that these ideas do not apply directly to our circumstances). It is relatively understood that HIV can speed up HCV disease but not much is known as to whether HCV can speed up HIV disease. Below are some pros and cons for when to start treatment for either HIV or HCV in people who are co-infected:

1. Treat HCV first?
- If the CD4 count is less than 100, only treat if the person is intolerant to HIV drugs.
- Eradicate HCV first and then treat HIV which might help to increase CD4 cells with HIV drugs later.
- Treating with monotherapy pegylated interferon can decrease the impact of HCV on the liver and reduce the effects of liver toxicity from HIV drugs.
- Pegylated interferon has an antiviral effect on HIV and can reduce the HIV viral load by around 0.8 log.

2. Treat HIV first?
- Treating HIV improves that immune systems response to HCV.
- Treating HIV decreases the effect of HIV on liver disease.
- HCV is harder to eliminate in people with HIV (i.e. wait to treat the HCV)

3. Treat HIV and HCV together?
- Not recommended unless there is no other option.
- Only do this if the CD4 count is low and the toxicity of the HIV drugs is known in the patient.
- Treating HCV in early stage liver disease has better outcomes.

SMART Study Update
The SMART Study is investigating what the differences may be between continuous HIV drug therapy versus those people who take regular breaks from their HIV drugs. So far the study has enrolled 4113 participants worldwide with the aim of reaching 6000 participants by March 2006. Participants will be followed for 6 to 9 years. Australia only has another 39 people to enrol to achieve the Australian quota for the study. A high proportion of the participants are women (25%).

Pravastatin for lowering cholesterol?
Protease inhibitors have been shown to cause an increase in cholesterol in the blood. Pravastatin is a cholesterol lowering drug that appears relatively safe to use with protease inhibitors. St Vincent’s Hospital enrolled 33 people with HIV into a 16 week study who had an undetectable viral load and a cholesterol above 6.5 to test whether taking pravastatin would be able to reduce cholesterol. All participants followed a cholesterol lowering diet. 16 were placed onto pravastatin. Results showed that those on pravastatin only achieved a 0.3 (mmol/L) lower cholesterol than those not taking pravastatin (-1.0 vs -0.7mmol/L). Thus pravastatin was not considered to be an effective cholesterol lowering agent for people with HIV. Dietary intervention was considered to decrease cholesterol significantly.

Results from the Pulse Study
In previous years a drug called hydroxyurea (HU) had been used to increase the efficacy of the HIV drug ddI. There was even a report of one person in Berlin who stopped and started treatment with HU + ddI + a protease inhibitor and who managed to return an undetectable viral load after cessation of treatment. This lead to the idea that maybe there was something a little different about HU. HU acts a little like an immune suppressive drug and reduces adenosine, a DNA building block, inside cells. DdI mimics adenosine inside immune cells,
thus reducing adenosine increases the antiviral activity of ddI and also decreases the ability of human cells to replicate. HU is primarily used for treating cancer. However, HU fell out of favour when the ACTG 5025 study was terminated due to significant problems with toxicity. The Australian Pulse study was designed (before the 5025 study results were released) to see whether starting and stopping treatment could enhance the bodies immune response to HIV. The study drugs used were ddI + 3TC + ritonavir boosted indinavir with or without HU in 68 people who were newly infected with HIV (acute and < 6 months). Study drug was taken for the first 12 months followed by up to three treatment breaks where treatment would commence if the viral load increased to greater than 5000 copies. Responders were recorded as those with a viral load less than 5000 copies two years after stopping treatment. Results showed that there was no difference between the HU groups for those having to recommence treatment. By the end of the first year after treatment breaks 25% had recommenced treatment and 50% of people had recommenced treatment by three years. Interestingly people who commenced treatment during acute HIV were less likely to have recommenced treatment.


Growth Hormone improves CD4 counts
New CD4 cells develop in the thymus gland under the breast bone. Children tend to have quite a large thymus gland but the gland shrinks and tends to become less functional as we get older. Recombinant human growth hormone (rhGH) was recently tested in 60 people with HIV who had a blunted CD4 response to antiviral therapy. RhGH increased CD4 cells by 55 over 6-12 months. The thymus gland was shown to increase in size in 14 of 20 patients tested. [Editor’s note: RhGH is not readily available in Australia. It can be purchased but is very, VERY expensive.]

Stay on 3TC during a treatment break
A 48 week Italian study was presented showing that people with resistant HIV are better staying on 3TC than people who stop taking all of their HIV drugs. 50 people HIV drug resistance including the mutation associated with 3TC resistance were randomized to either stop all of their HIV drugs or to continue with 3TC monotherapy only. After 48 weeks, results showed that those continuing with 3TC had less of an increase in viral load (0.67 log versus 1.23 log) and less decline in their CD4 cell count (143 cells versus 189 cells). Less people taking 3TC had to restart HIV drug therapy over the study period than those not taking 3TC (41% versus 69%).

Tipranavir + T-20
In a sub-study presentation of the RESIST study, researchers investigated the amount of the tipranavir in the body and matched this with virological results in heavily pretreated patients. When the amount of tipranavir in the body was more than 60 times above that known to inhibit the virus Inhibitory Quotient = 60), and when T-20 was used for the first time, 81% of patients achieved a reduction in viral load of more than 1 log (a 10 fold reduction in virus). Furthermore, nearly 60% of these patients achieved an undetectable viral load (< 400 copies) by week 24. [Editor’s note: Using T-20 for the first time with a new protease inhibitor is proving to be an effective HIV management tool for many people. Tipranavir is available through an access program for people with a CD4 count < 150.]

New Kaletra tablets
Abbott presented information on their new version of Kaletra. The new tablets have lopinavir and ritonavir blended through them using a new technology called ‘Meltrex’. The drug levels between the old soft gel formulation and the new tablet were considered to be comparable with less variability in drug levels for the tablet version. The new tablet had fewer extreme high and low levels of the drugs in the blood and there were fewer side effects. The new tablet does not require refrigeration and only 4 tablets are required each day, down from 6 capsules for the old formulation.
Treatments Update: what’s new, what’s changed

New NNRTI by GSK
Data was presented from a GlaxoSmithKline dose ranging study on a new NNRTI (like nevirapine or efavirenz) that has activity against resistant virus. Normally when the virus becomes resistant to one NNRTI it is considered to be resistant to all NNRTIs. This study clearly showed that the new GSK drug, GW695634, was highly effective at reducing the viral load (-1.1 to -1.6 log) after 7 days monotherapy treatment in people who had resistance mutations to nevirapine or efavirenz.

Reverset data
Reverset is a new NRTI (like 3TC) that is thought to have activity against NRTI resistant virus. In the study presented reverset or a placebo was given to 199 people who were on a failing antiviral regimen. The viral load was reduced the most in people taking the 200mg dose (-0.7 log). However the activity of the drug was greatly reduced in people who were taking 3TC or FTC which indicates that an unfavourable drug interaction was taking place or that the drugs were not working effectively together. When these people were removed from the analysis reverset was shown to reduce the viral load by 1.1 log. Most side effects were considered to be mild and included headache, fatigue nausea and diarrhea. Those taking ddI with reverset led to an increase in lipase in some people leading investigators to believe that damage may be occurring to the pancreas in people on this combination. There were 4 reports of pancreatitis in the study (not a good thing to get). Interestingly some resistance mutations were shown to decrease the efficacy of reverset such as AZT like mutations (TAMS with the 3TC mutation (184), and a ddI (74) or tenofovir (65) mutation. TAMS alone or 184 did not reduce the efficacy of the drug.

In the News

PA-457 results
In late August Panacost Pharmaceuticals released data from the phase IIa study of PA-457. PA-457 interfere with the production of the HIV capsid protein that is required to package the virus when it leaves infected cells. Results in the dose ranging study showed that PA-457 reduced the viral load by an average of -1.03 log (90%) in people taking the 200mg dose at day 11. The result was better in people with a viral load below 100,000 copies/ml (-1.5 log).

NNRTIs and treatment breaks not good
A study in Spain investigated 45 men who taking an NNRTI (drugs like efavirenz or nevirapine) before taking a treatment break has shown that only 44% of people (n=34) who recommenced treatment with an NNRTI achieved an undetectable viral load. The remaining 11 patients who recommenced treatment with a protease inhibitor in their HIV combination all acheived an undetectable viral load. [Editor's note: This study shows that taking a break from treatment while on an NNRTI regimen can lead to viral resistance and viralogical failure. Because NNRTIs hang around in the body for up to 3 weeks after stopping them it is probably a good idea to switch to a protease inhibitor for 3 to 4 weeks before taking a treatment break. Always talk with your doctor first before taking a treatment break.]

Protease inhibitors may stimulate new CD4 cell production.
A study published in AIDS in 7 people receiving PEP (post exposure prophylaxis) has indicated that protease inhibitors may increase the production of new CD4 cells from the thymus gland. The thymus gland is situated under the breast bone and is responsible for the maturation of new immune cells. The protease inhibitor used in this group of people was nelfinavir. New CD4 (T-cells) increased in 5 of the 7 patients treated. None of the patients became infected with HIV. Investigators concluded “the data indicate that the net effect of antiretroviral therapy is an increase in thymic output and a rejuvenation of the T-cell compartment”.
Membership application

All details contained herein will be treated strictly confidentially.

I wish to become a member of People Living With HIV/AIDS Victoria and to receive all privileges of said membership. I agree to abide by the Rules of the organisation at all times. I give permission to receive information from PLWHA Victoria.

Full Membership: I am HIV positive and am able to provide verification of this if required.

Associate Membership: I do not wish to disclose my HIV status, I am HIV negative or I do not know my HIV status.

Signed

Address

Telephone (optional)

E-mail address (optional)

Please fax or post your membership application to: PLWHA Victoria

*Copies of the Rules of the organisation are available from the PLWHA Victoria office.

PLWHA Victoria’s Annual General Meeting

Positive Living Centre
51 Commercial Rd, Prahran

Sunday 27 November
1.30 pm

Join us for an annual review of the activities of People Living with HIV/AIDS Victoria. Election of board members, presentation of Annual Awards and acceptance of reports and financial statements. All welcome.

All members and supporters of PLWHA Victoria are encouraged to attend.

Acknowledgement

PLWHA Victoria would like to thank our sponsors for providing unrestricted educational grants to fund Poslink and Treatment Interactive Events in 2005.
Sexually Transmitted Infections RoadShow

An information evening on sexually transmitted diseases for people with HIV

Recent media reports have highlighted rising rates of sexually transmitted infections among gay men. This workshop will highlight some information around this topic and, in particular, the impact that STIs may have on people living with HIV.

Presenters
Dr Darren Russell
& Mr Phillip Keen
(Australian Federation of AIDS Organisations)

Tuesday 22 November, 7—9 pm
Positive Living Centre
151 Commercial Road
Prahran

For further information please call Alan on 9865 6718.

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Vanessa’s Christmas Nosh

An update on new HIV treatments with Dr Jonathan Anderson and other guests.

Sunday 11 December, 1 to 6 pm
Vibe Café and Bar
123 Smith Street
Fitzroy

Free drinks, food, door prizes and end of year party.

For further information please call Frank on 03 9865 6772