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POSLINK

The Newsletter of People Living With HIV/AIDS Victoria

Brent Allan at the slave auction

Issue 19 Oct / Nov + 2004

Inside this issue:

Extreme Makeover: The Life In Balance Method

At PLWHA Victoria's recent Treatments Interactive Event, Extreme Makeover, the services of a Life **In** Balance facilitator were engaged to impart motivational techniques from the 'Life **In** Balance Method' to assist with developing and implementing life goals. Although tempted to 'strike a pose' with his Madonna-like head set during his slick presentation, our Life **In** Balance facilitator, Josh Ciechanowski, put forward stacks of information to our audience about the things that hold us back from achieving many of our goals, before presenting us with motivational techniques to help push us through our barriers of multiple excuses and procrastinations, in order to reach our goals. The following article is a representation of the Life in Balance Method put forward by Josh who held his captivated audience in the palm of his hands for the duration of his talk.

"The 'Life in Balance Method' is interested in where you are today and where you want to get to, by helping you put together a strategy that you can adopt to move forward and create the things in life that are really important to you," said Josh.

The interesting thing about human beings is that most people already know how to live a balanced, fulfilled, happy and successful life. But things tend to get in the way of us moving forward. In order to understand why this is, it is important to understand failure. Failure usually results from procrastination.

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Note from the Executive Officer

Mark Thompson

It has been very busy at the PLWHA Victoria office in the last two months. Our recent Treatments Interactive Event was a great success and held the audience rapt with attention for well over two hours. Alan Strum's articles on the afternoon provide exceptional coverage of the advice which was presented on the day. In addition, we have been preparing our annual report and for our Annual General Meeting. We hope to see many of our members at the meeting on Sunday 17 October at Vibe Café and Bar.

In addition we have had quite a call on our Emergency and Distress Fund from HIV positive people experiencing financial distress. The fund provides grants of up to $50 per annum which can go towards food, utility bills or transport costs such as car repairs for HIV positive people on a pension or unemployed. While not as big a fund as the better-known David Williams Fund, our E&D fund can offer assistance immediately for those unforeseen financial crises. We are also delighted to let members know that we have been given assistance through the Telstra Bill Assistance Program. These are certificates which entitle a person to a $25 credit adjustment against their fixed lined home telephone account. If you need assistance with your telephone account, please call the office on 9865 6772. Any assistance given will go towards your $50 limit per annum.

We would like to thank Telstra and Country AIDS Network for their generosity in sharing this program with PLWHA Victoria.

As the president has alluded to in the report, there have been major developments in our funding situation. The Department of Human Services has confirmed an increase in direct funding to the organisation which will enable us to employ more staff so that our programs can reach their potential. We have already advertised for new positions, Administrative Assistant and Community Development and Education Officer, and we have had confirmed that our Treatments Officer, Alan Strum is funded full-time and that the Speaker Bureau position is now a separate position funded at four days per week.

In addition we have received $50,000 to implement an innovative positive education program in the coming months. Planning has started on this project and details of the launch and project will be in the next edition of Poslink.

We would like to thank the Department of Human Services for their expression of confidence in the future of the organisation through their funding decision and our ability to implement vital education programs for and by HIV positive people.

Note from the President

John Daye

This will be my last report as President of PLWHA Victoria as I am retiring from this position after this year's Annual General Meeting. Over the past year my work in HIV treatments both at a national and international level has expanded considerably, and I have been working virtually full time in advisory roles. As such I have decided it is time to pass on my leadership role within PLWHA Victoria to a new President. I want to thank all those individuals I have worked with over the 8 years I have been President, without whom our achievements would not be possible.

This past year has seen some great innovations within the organization. Most particularly Board member Guy Kharn who, despite some considerable hurdles, managed to get *Positive Plots* off the ground with support from his partner Steve Wiggins. *Positive Plots* was launched by Deputy Premier and Minister for Victorian Communities John Thwaites recently in St Kilda.

The past year has also seen our organisation's first involvement in international HIV work. Through the National Association of People Living with HIV/ AIDS, Max Niggl and Andrew Timmins took part in The Collaboration for Health in Papua New Guinea Project. Both Max and Andrew participated in a facilitated study tour to understand the role of day-care centres in response to the HIV epidemic in PNG. I want to commend them on their outstanding work.

I want to thank our staff for their hard work throughout the year. I would like to thank Mark Thompson, our Executive Officer, for his level of contribution throughout the year. Also, Alan Strum, our Treatments Education and Policy Officer, has established high levels of treatments expertise within the organisation and has done an excellent job coordinating the highly successful treatments interactive events and editing of our publication Poslink. I also want to thank Max Niggl for his administrative support which has always been timely and efficient and commend him on his work with the Speakers Bureau both at a state and national level.

In particular I want to thank David Menadue for his immense support and advice while I have been President. The drafting of our submission to the review of PLWHA Victoria was primarily written by David Menadue and myself and the legacy of this work is seen in recent recognition and improvements in the resourcing of the organisation. In this respect the organisation is in the strongest position since I became President.

I want to thank all our volunteers and sponsors for the many hours of commitment and support they have given to PLWHA Victoria and the positive community.

I want to thank the Board who have worked hard to improve the quality-of-life of HIV-positive people in Victoria by representing their interests on countless committees and organisations.

PLWHA Victoria is only as strong as the HIV positive people who involve themselves in its work. We can all effect changes that improve our lives in living with HIV and I encourage everyone to play whatever role you can to make our world a better place to live in.

What's Up, News and Information

Syphilis on the rise: go get tested

Victoria has mostly been saved from the syphilis epidemics that have been plaguing some Australian states, with only 58 cases reported in 2003 compared with 827 in NSW, 324 in the NT and 376 in QLD. However, the first 3 months of this year saw 19 cases of syphilis reported in Victoria which was more than double the number that had been reported in the last 3 months of 2003. This has sparked concerns among health officials that extra testing and awareness of syphilis was required in order to ensure this sexually transmissible infection would not get out of hand in Victoria. The majority of Victorian cases had been identified in men who have sex with men, and there also appeared to be a relationship with some sex on site premises. Some sex on site premises in Melbourne already offer regular sexual health services and testing. With the new figures on board, the Department of Human Services expanded syphilis testing into other venues on a temporary basis where testing had not previously been available.

The problem with syphilis is that people often don't know they have been infected and appear to remain healthy for a number of years before damage to the body starts to occur. Early symptoms include a painless chancre or blister on or around the genitals, the mouth or anus. Later symptoms include a rash on the body, hands or soles of the feet, and/or losing tufts of hair. Syphilis is easily diagnosed and treated. However, if left untreated, especially in people with HIV, it can quickly begin to cause damage to some of the major organs like the brain or the heart.

Condoms help to reduce the risk of catching syphilis but don't eradicate the risk. The only way of being sure that you don't have syphilis is to be regularly tested. In San Francisco where syphilis numbers are increasing quickly, it is now recommended that sexually active gay men be tested for syphilis every 3 or 6 months. Being tested for syphilis regularly is the best way of protecting your health.

Victoria to start an HIV brain bank

There are many things about HIV and how it affects the body that we still do not have a good understanding about. Its affects on the nervous system and the brain is one of the areas that requires lots of research in the era of people living longer with HIV. In reality we just don't know what the long term affects of HIV on the brain are, and this area must be researched thoroughly to ensure all PLWHA needs are met.

It is in this context that the Australian National NeuroAIDS Brain and Tissue Bank (ANNBTB) has been set up. People who volunteer to participate in this project will get to have neurological and psychoneurologic testing done every 12 months to track any changes that may be occurring in their nervous system from HIV. The testing procedures are quite thorough and will take approximately 4 hours at each yearly visit. The neurological assessments will then be compared with the brain tissue. Yes, that's right. You read correctly. This study requires participants to provide consent for a number of body tissues including the brain to be taken at death, if and when death occurs. As such the study is expected to continue for quite a while. Body tissues will be made available for legitimate research purposes only.

Genetic testing for markers of disease will also be performed, which means that any underlying undiagnosed diseases might be identified. On one hand this could be viewed as a good thing. However, ethically and legally, any identified genetic disorders can become a little sticky, as this type of information often needs to be passed onto insurance companies for anyone applying for health or death cover policies etc. Also, there is no accounting for future laws that may impact the confidentiality of genetic information.

If you can get your head around the grey areas regarding genetic testing, this study really is quite a remarkable way for Australian researchers to access and study human tissues. This can only help to improve our knowledge on what the virus is doing inside the brain and pave the way forward for future PLWHA health care, services and research.

If you would like more information about participating in this study please call Fairlie Hinton on 03 8344 1900.

What's Up, News and Information

Abbott Laboratories price increase assessed by NIH

Earlier this year Poslink informed you of the 400% ritonavir price increase in the USA. A group in the USA submitted a petition to the National Institutes of Health requesting the patent for ritonavir be revoked from Abbott on the basis the company had received financial assistance from the US government to develop the drug in the early 90s. Under these circumstances a company is to ensure reasonable availability of the drug to the US population as stipulated by the Bayh-Dole act. The petition was rejected in August by the National Institutes of Health on the grounds that the dispute was about price and not availability, and was satisfied the company was meeting its obligations under the act. The Institute advised that Congress would be better suited to address the issue of price.

Slave Auction success

This years Slave Auction at the Laird Hotel was a tremendous success with over 500 people attending the event and 22 slaves sold to raise money for the Victorian AIDS Council and The David William's Fund. $8,500 was raised at the event with the highest bid of the evening being for the manager of HIV Services at the VAC/GMHC, Brent Allan, who bravely strutted his stuff on the stage in full military regalia. And Brent's price.....$600, thanks Chris Sayers of Tessa Furniture!
(Brent is this months cover boy)

Free Massage Reminder – make your booking now!

For those lucky people who obtained free massage vouchers through Poslink, the Treatment Interactive Event or Planet Positive, please book your massage now before the expiration date of 3 November 2004. Sessions are currently available but will get booked out quickly. Anyone who does not book there message now will most likely miss out as sessions are limited.
CALL FOR AN APPOINTMENT NOW ON 03 9421 3303.

People with Living HIV/AIDS VIC

Annual General Meeting Notice

Members of
People Living With HIV/AIDS Victoria are invited to the Annual General Meeting

1.30 pm Sunday 17 October 2004
Vibe On Smith Cafe Bar
123 Smith St Fitzroy

Business to be conducted includes election of board members, presentation of Annual Awards and acceptance of reports and financial statements.

Community Letters: The Scratching Post

The Scratching Post is your connection to the community. You can write to us to share information or voice your opinion or concerns on issues that affect the HIV community at scratch@plwhavictoria.org.au

Dear Poslink -What's the deal with Public Housing?

As I flew over Melbourne recently I could not help but admire the views of this beautiful city that we live in. From a distance, the planning of Melbourne made it appear so organised and structured. I was in awe with the site of the view of beautiful parklands and gardens. As we came into our descent, I began to see the old grey concrete towers that constitute so much of the public housing in Melbourne. The sight of which reminded me to do as I so often do when driving or on a tram or train – to turn and look the other way.

On the way home from the airport, I drove through the inner suburbs of Carlton, Collingwood and Richmond and again looked the other way, turned the radio up, start a conversation with my fellow travellers – anything to distract myself from the reality of what was only just metres away. It was then that I saw a person that I was able to identify as possibly having an HIV related illness and I was confronted by what so many people call their reality every day. I could no longer turn away.

At that point I asked myself the question "What is life like for PLWHA who live in those buildings? And what happens to PLWHA that have no place to call home?" It was not until I was sorting though some old papers and talking about the public housing with friends and colleagues that I realised just how much of a problem public housing has become in Melbourne.

I have read of stories of gay men, many of whom are HIV positive, being bashed and suffering vile discrimination due to homophobia and AIDS phobia by other tenants in public housing. Many of these people feel they are unable to take action or report incidents due to fear of recrimination and more violence. Those who do take action against the violence more often than not are forced to become prisoners in their own home, too afraid to leave the premises to even undertake basic tasks such as going to the Doctor or doing their weekly shopping. What is our government doing for these people?

I have also heard stories from people who currently live in public housing about units being closed for maintenance for extended periods of time. Apparently some have been closed for as long as two years that are officially undergoing maintenance but are really being held for people who will be eligible for public housing but who are employed. The current thinking is that the Department of Housing is attempting to change the 'culture' of the blocks by only accepting tenants whom they perceive will be able to pay their rent on time. Meanwhile many PLWHA are homeless!

A friend of mine tried to get assistance from the AIDS Action Housing Group (AHAG). To my surprise AHAG were unable to offer transitional or short term housing to them. Other resources and agencies appear to be stretched beyond capacity. Essentially it appears that there is no more room at the inn! It also seems that there is insufficient support from the Government and the Department of Housing to assist organisations such as AHAG that provide such an important service.

In primary school, I was taught that there were 3 basic human needs – food, clothing and shelter. Surely in this day and age that is not a difficult thing to ask for! So, what is our government doing about public housing for PLWHA? Surely it would make sense for the department of housing to provide a few small housing blocks to AHAG for the exclusive use for PLWHA. Wouldn't this solve many of the problems?

Silence still equals death!

Name and address withheld

[*Editor's note: PLWHA Victoria is awaiting the release of the DHS-funded Housing Review for plwha which we are hopeful will contain some recommendations to improve the difficult situation facing plwha trying to get appropriate public housing currently. We fought for this review to happen because we are aware of the problems and current housing shortages and we will fight to see changes made after the report is released.*]

Lifestyle Hints and Tips

By Frank Dimitriou

It's time to shed the familiar winter activities that we've become accustomed to and enjoy the onset of summer. Here are a few suggestions that might get you started.

- Just like the birds and the bees, everyone seems to be kissing and cuddling everywhere you look. Spring is the time of new and renewed love, and after the winter hibernation, it's time to venture out and spend time with the ones you love.

- Break out of your winter shell and do whatever it is you need to do to make yourself feel good about being you. Some may get their hair done while others may enjoy a manicure or pedicure. What ever it is, it must be designed to wipe away those old winter cobwebs and make you feel spunky and ready to take on the world once again.

- It's time to discard the old and revel in the new. Put away those thick and heavy jumpers and jackets and break out the shorts and T shirts. Air out your summer clothes and perhaps do a spot of shopping to update your look. A stroll through the city or Chapel street will give you an insight into what's hip. And remember it's our diversity that makes us each unique and trendy.

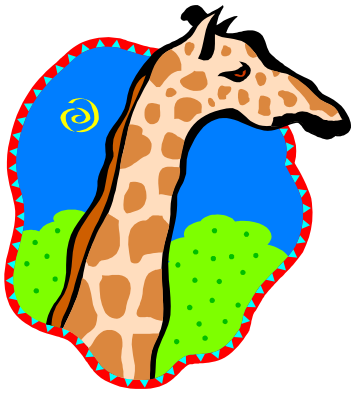
- Spring cleaning. Yes it has to be done, and as well as a general once over for your comfort space, think about making a change to coincide with the new season and possibly the new you. Rearranging a few choice pieces of furniture can make a world of difference. Hanging a new print can also have a huge impact on how a room or even your whole home feels.

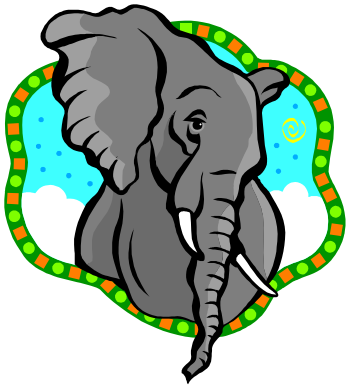
- Get motivated and enjoy the fresh crisp spring air by walking though your local botanical gardens or even just a walk around your local neighbourhood. Perhaps save some stale bread and go feed the baby swans at Albert Park Lake or the ducklings in a local park pond.

- Don't forget, if your one of the many who fall victim to the airborne pollens that cause hay fever, stock up on your favourite antihistamine and save yourself the teary eyes and sinus problems. Just make sure it's safe to use with your HIV meds.

- Visiting the Melbourne Zoo with friends can be a great day out. There are some new exhibits and it's a great opportunity for exercise as you stroll around enjoying your day watching the animals and all the newborns.

- Consider organizing a regular meeting with friends in an outdoor café or beer garden or possibly start up a breakfast club. It can be a great way of maintaining friendships and enjoying the fresh air. Remember to choose its location carefully as a well selected venue can offer hours of eye candy.





Special Feature
Extreme Makeover: The Life In Balance Method

(*Continued from page 1*)

There are four stages to the failure cycle:

Stage 1: Excitement

Though it sounds strange, failure starts with excitement. "We have a vision or a view of something we want to create, have, be or do in our lives. We can see the outcome that we are embarking upon and we can see the benefits in our lives so we get excited. We start to do the things that are required of us to be successful," said Josh.

Stage 2: Avoidance

During the excitement stage some people tend to go a little bit off track which takes us to our next stage in the failure cycle which is called avoidance behaviour. This is where people delay or defer and put things off to another time.

If people are aware of their avoidance behaviour they can move back into the excitement phase. But most people don't know that they are doing it so then they start to make excuses.

Stage 3: Excuses

Excuses are warning signals that should be recognised as things that get in the way of people achieving their goals. Examples of excuses are; it's too cold outside, I'm too tired, I don't have enough time, or I don't have enough money etc.

Stage 4: Blame

The fourth part of the failure cycle that stops people from achieving their goals is called blame. Blame is what people do when they don't accept responsibility for their own actions or inactions. It is a negative aspect of removing personal responsibility and holding something or someone else responsible for not being able to achieve ones goals.

"For me to live a balanced and fulfilled life and to get the things done that I know I need to do, the external circumstances really don't amount to a whole lot. In fact it is up to me and my own internal thinking, my own creativity and my own power to create the life I want to live," said Josh.

It's important to understand that lots of people 'fail' to achieve their goals from time to time. Failing is not necessarily a bad thing. However, it can become a concern when a person continuously fails with a repeated pattern throughout their lives. This is usually associated with a life full of excited starts and incomplete finishes with people never taking the time to stop and assess the reasons behind the repeated behaviours.

In order for people who are consistently failing to move forward to achieve their goals it is important to understand what forms the basis of the avoidance cycle. Procrastination leads to avoidance. There are four main reasons why someone might be a procrastinator:

1. People set the wrong goals for themselves.

It's really important that people set the right sort of goals for themselves that are within their abilities to achieve. Starting off with small achievable goals builds confidence and can lead to people setting bigger goals to stretch their boundaries.

2. Having an unclear focus

People can be unclear about the things they want to 'have, be or do' in their lives. It has been said that 'Weak and scattered thoughts are weak and scattered forces. Whereas strong and concentrated thoughts are strong and concentrated forces.' Trying to achieve too many goals at the same time can disband a person's energy. People need to realise that minds are like magnifying glasses that can concentrate energy or light into one small spot with the correct focus. Josh said, "If you find out where you are going you will have more focus, more energy and more clarity for moving towards the outcome that you want to create for yourself."

3. Not having an action plan

To achieve goals it is necessary to work out where you are going and how you want to get there which is different from a dream. To do this people can set up 'macro' steps or goals of things they want to achieve or have. Then small strategic 'micro' steps are the things that are planned or scheduled in order to reach the 'macro' step or goal. People probably shouldn't set more than 3 or 4 macro steps at any one time otherwise they might lose their focus. Take the time to work out the micro steps.

4. Having mental barriers or blocks

Mental barriers or blocks come from the experiences people have been exposed to from their past. This often includes the things that have been told to them by parents, teachers, peer groups or the media. An example of the seed of a mental barrier may have been a teacher or parent telling a person that 'they would never amount to anything' etc.

Mental barriers essentially come from the past and people tend to become quite familiar and comfortable with them. A way of understanding procrastination a little better is to talk about the life line by which

people live. The life line consists of three components:

- The past (most of us)
- The future (some of us)
- And the now

Most people tend to live in the past, reliving or thinking memories and feelings. Some people dream about the future. The most fundamental moment in time for human beings to bring about change in their lives is to be in the 'now'. By living in the past people lose sight of the things that can be achieved in the future. Josh said, "the now is the moment, the second, the instant you give energy to a thought. It is the only moment you have any power in your life and you have complete dominion over it. Each and every conscious thought you think you can insert any thought of any type you like in your mind. What you see you become. What you dwell upon all day long becomes more real to you in your life." The human brain thinks 40,000 to 60,000 thoughts every day. These thoughts can either be focused on the past or they can look towards the future to identify the things that can be achieved and then develop thoughts everyday about achieving those goals through development of an appropriate action plan with micro and macro steps and positive affirmations.

There are the three steps and tools people can use to bring about positive change in their lives:

1. Create a vision for yourself
Create a strong and clear vision for yourself with something that really inspires you that has 'pulling power'. Move your attention and focus away from the past and start looking towards the future.

2. Become other people centred
This is the opposite of self centeredness. Choose to do things that help other people for the benefit of other people. When people see someone doing something designed to help other people they tend to get behind that person and help to push them along (pulling power). Being self centred tends to create pockets of resistance and reduces opportunities.

3. Gain mastery of the mind through preferred realities
A third way to bring about change is to gain mastery over the mind or inner world. This can be achieved through meditation-like techniques that can be used by your mind to get to where you want to go. One method of gaining control over the mind is via preferred reality conditioning. Reality is the result of decisions that are made during ones lifetime in response to the environment. People also have a preferred reality. "We have the ability to change our thoughts and ultimately change our behaviour. By changing our inner attitudes we can change the outer manifestations of our lives," said Josh.

There are three quick steps to preferred reality conditioning:

1. Understand the power of visualisation
Visualisation is perhaps the most powerful mental faculty people have available to them. Get some strong visual images that represent what you want achieve or become like a picture of a body builder, and put your face on it. Surround yourself with positive representations of what you want to create.

2. Understand Script
A script or affirmation needs to be a short sharp personalised positive present tense statement that you repeat to yourself to bring about change. You need to come up with a new script such as 'I get everything done that I need to get done today'. This has to be repeated over and over again every day.

3. Utilise the alpha mind
The alpha mind is a state of being that makes it easier to accept changes in your life. Certain types of music can evoke the alpha mind state such as *largo* tempo music from baroque concertos (slow peaceful music) or meditative music. Do the visualisation and script techniques while listening to the music.

Ultimately, people already know what is required in order to lead happy healthy and fulfilling lives. By setting the right goals with a clear focus, developing and implementing an action plan in the 'now' with micro and macro steps, creating a vision with pulling power to help other people, and developing preferred realities with positive reinforcement of self through visualisation and scripting, people can move forward to achieve whatever their heart desires, leaving repeated behaviours of failure where they belong in the past.

Our thanks go to Life In Balance Seminars for providing the methodology presented by Josh free of charge to PLWHA Victoria for this presentation. Our thanks also go to Josh Ciechanowski for providing his services free of charge for the Extreme Makeover forum. For further information, Josh can be contacted on 0411 951 661 or visit the Life In Balance website at www.lifeinbalance.com.au.

Special Feature
Extreme Makever: Vanessa's guide to a new you

Extreme Makeover was the title of the recent PLWHA Victoria Treatment Interactive Event. We have become used to the term 'extreme makeover' from the TV show about changing your outside appearance. Our aim for this event was to focus on changes on the inside – in the mind. We wanted to get people to alter the way they think about health and lifestyle changes by focusing on changes as goals, by using visualisations and 'scripts' or positive affirmations as a way of obtaining those goals. Our host, Vanessa Wagner, guided our participants and expert panel through four unrelated scenarios. Dr Kate Cherry provided medical advice, Jenny McDonald provided nutritional advice, and our personal development facilitator Josh Ciechanowski assisted with hints on implementing lifestyle changes. The following is a summary of the information discussed and, as such, should not be interpreted as direct quotes.

Scenario 1: Smoking

Greg's Story
I have been very successful at giving up smoking — I've given up five times in the last year! Smoking pisses me off but I also enjoy it which I guess is the addiction. I understand that smoking is bad for me and I really do want to give up. And my doctor has been telling me that the chances of having something like a heart attack later in life are higher because of my HIV drugs. But I don't really understand this.

So, can you tell me why smoking is worse for people with HIV and what's the best way to stop for good?

Response from the panel

Dr Kate Cherry
Basically, smoking kills people slowly. For people with HIV who were smoking 10 years ago before the introduction of effective treatments the attitude was that if you enjoy it, do it. These days people with HIV are living long enough for smoking to cause cardiovascular disease that can result in heart attacks or strokes or they can even get lung cancer. There is evidence now that the HIV drugs do increase the risk of cardiovascular disease. There are a number of big international studies that have been following people with HIV on treatment. These studies have shown without question a much higher incidence of heart disease over and above the general population and the incidence increases with each year of antiviral therapy. Because smoking adds to the risk of heart disease, not smoking becomes one of the few things that people can do that is within their control to reduce the chances of developing heart disease. I also think smoking is incredibly expensive. I can't tell you how many times my patients complain to me about the cost of medication and then go out and spend up to $50 a week on cigarettes that are killing them. If they were to put that money aside each week, at the end of the year they would have a return trip to Europe paid for. We have to remember that giving up smoking is one of the hardest things anyone will ever have to do. It is my observation amongst my patients that those who successfully give up smoking are those who acknowledge that it is difficult to give up and prepare for that. There are medical interventions available to alleviate or prevent the nicotine withdrawal symptoms that people might experience when they stop smoking.

Jenny MacDonald
You can buy a lot of good food to help you put on weight for the amount of money you spend on cigarettes every week. I get really frustrated when the cigarettes take the place of good nutrition. Good nutrition will improve your immune system and give you long term better quality of life. If you are a smoker it is important to have extra vitamin C because smoking takes more vitamin C out of the body than non smokers. If people smoke marijuana to help with appetite then they are better off putting it into food so they are getting nutrition at the same time as increasing their appetite.

From left to right: Josh, Jenny, John Daye, Vanessa and Dr Kate

Josh Ciechanowski
First and foremost to not smoke starts with a decision not to smoke and no amount of coercion or strategy you put in place will succeed otherwise. It becomes easy to sabotage the attempt to stop smoking on a subconscious level. Stopping smoking often amounts to giving up something that you feel you really want. I would encourage focusing on the positive of what you want and what you want to move towards. Rather than giving up smoking, think about only ever doing positive things for your body, of which smoking does not quite fit into. If you smoke, one of the quickest ways you can increase your longevity and quality of life and how much you can taste food etc is to give smoking away. I would recommend firstly making a decision to give it up. Once you make a decision to stop you might want to use affirmations and visualisations. See yourself not smoking, breathing in healthy fresh crisp air, and you can repeat to yourself that 'I only ever do healthy things for my body.' Do that on a regular basis or whatever script you think will work for you. Eventually, if you do that long enough your mind will accept it, and if you pick up a cigarette your mind will go 'hang on, I only ever do healthy things for my body.' There are also good resources around like the quit line (131 848 or www.quit.org.au) who offer really good tips on how to stop smoking.

As people go through the change process they tend to have an all or nothing approach towards change. They think that if they slip, that they don't have the ability to follow through and then give up. The process of change involves regression as part of that process so there should be times when you slip up. But if you anticipate that slipping up is part of the process and then refocus on the goal after slipping up, then you will find your general pattern of behaviour will start to change.

Advice from the audience
I used to smoke 40 cigarettes a day and was able to stop smoking after reading a book called 'The Easy Way to Stop Smoking' by Alan Carr. Since not smoking I have gained weight. The book seems to speak directly to the subconscious so you want to stop smoking over time.

Scenario 2: General Health

John's story
I have been noticing the years going by lately and I have to say I'm feeling a bit slow and run down. My antivirals are working well and the virus is under control. So what do you think I should be doing to have more energy to do the things I want to do?

Dr Kate
I think the first thing to do that is really important is to realise that if you are living with HIV you are living with a chronic disease. Having a chronic disease and taking the drugs will probably slow you down a bit. And you are older than you were 10 years ago and that may be part and parcel of what you are feeling. It's okay to feel a bit fatigued and that should be acknowledged. It probably wouldn't be a bad idea to have a check up with your doctor to make sure that there isn't something that is causing the fatigue. Sometimes things get over looked because the doctor is focusing purely on the HIV. Depression is often under-reported in people with HIV and can be responsible for people feeling run down and not eating

properly. It is my observation that those who make an effort to exercise and eat really well tend to do better in many ways. I see people's T-cells go up considerably over and over again in those people who take up regular aerobic exercise.

Jenny
People who live alone and who burn the candle at both ends often don't eat properly. I'd be looking at John's nutritional intake to make sure he is eating properly and I would also recommend that he take a good multivitamin every day like the Swiss Women's Formula multivitamin tablets. People with HIV have a higher requirement for B-complex vitamins which this multivitamin provides. I'd also be recommending regular exercise.

Often people start their day by missing breakfast and then don't eat until lunch time. Then they get busy and forget to eat at lunch time and end up with only one meal for the day later on which is not enough food to remain healthy. It's really important to have something to eat in the morning otherwise your brain forgets to send you the message that you are hungry. If you don't eat regularly then you lose the ability to recognise when you are hungry and have to retrain the brain to recognise hunger through eating by the clock and timing meals. If people don't feel like preparing food then just make a shake or have a milk coffee that you heat up in the microwave. This helps the brain to get used to having food and soon you'll feel like eating more food more often again.

Josh
I think most of us know that we probably need to exercise more than we do and eat better than what we do. A lot of us have associate exercise with pain and discomfort. We should find things to do that we enjoy doing and start out with baby steps like walking around the block for 10 minutes. Once you have your runners on and you are out in the fresh air moving around and breathing in fresh air you'll most likely keep going. Maybe it would be a good idea to find someone else who lives alone and take it in turns to cook for each other and turn eating into a social event.

Scenario 3: Returning to Work

Greg's story (take 2)
Recently I have been thinking about returning to work. I had a period where my T-cells were below 200 and I was very run down. I think I did the right thing having several years away from the stress of being in the workforce. Now I want to earn money again. I'm finding it very difficult to get myself back into the idea of doing a 9 to 5 routine though. I'm not sure whether it's psychological or whether it's HIV that's causing it but I don't seem to have the energy levels that I used to. I'm finding it hard to get motivated to go back to work and find a job. I just don't know where to start.

Dr Kate
Generally I advise people not to stop work if they can avoid it, understanding how difficult it can be to get back into the workforce. There are lots of people in this situation who weren't doing well and needed to stop working but who are doing well now and are ready to go back to work. I think people need to identify what steps they need to take to prepare for work. I would think about trying to structure your life as if you are someone who has a job. Look at having a good nights sleep. Get up early in the morning. Make sure your HIV medications fit into the work lifestyle you want and talk about this with your health care provider. Try volunteering a few days a week in an area that is related to what you want to do. When you are comfortable with the volunteer work maybe change to part-time work and then eventually to full time work. The process of getting back to full-time work may take some time. I think it would be reasonable for it to take anywhere up to two years to prepare for full-time work.

Jenny
If you live on your own you might as well cook for 4 or 6 and freeze the extra meals. Have food in the cupboard that you can easily throw together for easy meals such as pasta with some nice sauces or a stir fry. Get into the routine of making meals that you can cook in 10 to 20 minutes when you are feeling tired. People can come and see me if they need ideas around cooking easy meals.

Advice from the audience
Go and speak with the manager or owner of the business where you want to work. Introduce yourself to them and tell them that you want the job. Just sending in a resume doesn't do it. Offer to volunteer with them to get to know the job better. Then when it comes to hiring someone you are more likely to get the job than someone else because they already know you.

Josh
We tend to associate a lot of our confidence with what we do so when we stop working our confidence levels can go down. When you go through unemployment for a long period of time you can begin to doubt

that you can do a particular job. So be careful about what is going through your mind. When you start to get busy, even if it's not what you really want to do, you'll feel a tremendous amount of pride which will be a stepping stone for getting back to doing the things you really want to do. There can be problems with ageism in the workforce but older people have a lot more life experience and are mature, are less likely to get ruffled and more likely to be committed because they're not just there for a quick dollar. If an employer can't recognise that then they aren't the type of person you want to work for. I would encourage small steps by starting off with a casual or part-time position first to get back into the flow of things and to get your self-confidence back up again. Then slowly look for opportunities to extend the hours or find a second part time job.

Scenario 4: Sexual Behaviour

Alan's story
I've only recent seroconverted and it's been a pretty rough time. I realise that I made some poor personal choices around my sexual behaviour in the last few years and now I've picked up the virus. It's hard for me to admit this here but the truth is that I've learnt to like sex without condoms a bit too much and even though I know I'm positive now, I'm finding it hard to go back to using them again making me scared to have sex. Some positive friends have told me that I could find another positive partner and then it might be OK not to use condoms. But even then I've heard there's a problem with superinfection with HIV.

So, what is superinfection about and how can I learn to like using condoms again!

Dr Kate
When I discuss safe sex with clients there are a number of different things that I think are important. There is the public health issue where using condoms is the only way of containing the spread of the virus. And there is a lot of crap out there that you can catch by not using condoms and they are all on the rise. One client that I have, turned up with gonorrhoea, chlamydia and syphilis. People don't know they have syphilis unless they get tested and it literally rots the brain and rots the brain faster if you have HIV. So I think it is very important that you protect yourself from what's out there by using condoms.

The whole issue of superinfection is a tough one. What this means is that people who have HIV are not completely protected from catching HIV again. We know that superinfection happens and it has been documented as such, but we don't know how easily or how often it happens. One potential concern is that it might be possible to become infected with a drug resistant virus that will make HIV difficult to treat. The other thing that concerns me is that if you take one strain of HIV and give it to two different people, one can do really well while the other can lose T-cells really quickly. So it might be that your body is coping well with the virus that you have now but you might be able to catch another form of the virus through unsafe sex and not do so well. Maybe unsafe sex among positive people should be limited to committed long-term relationships rather than casual relationships, to reduce the possibility of catching another form of HIV. However, the information around superinfection is not clear cut, and I think everyone needs to make personal choices around safe sex based on all the information that is available to them.

Josh
You could break down your sex practices into little practical steps. Do little things that you feel comfortable with that might not include penetrative sex for now, then build up to using condoms over time as you become more comfortable with the idea of using them. Over time you should be able to learn to enjoy sex again with condoms. Perhaps a script that you could use to help you become comfortable with condoms is, 'I use condoms to protect my health and the health of others.'

Advice from the audience
I look at condoms as an empowering thing that means I can fuck freely. And every time I use them I get a good feeling that I am protecting my partners from the virus. Condoms allow me to feel good about myself.

Our thanks go to Vanessa, Kate, Jenny, Josh, Greg, John, Alan, Frank, Shane, Colin, Bernie and De who helped to make this day possible.

THE NEXT TREATMENT INTERACTIVE EVENT IS AT VIBE CAFE AND BAR, 123 SMITH STREET COLLINGWOOD, SUNDAY 5 DECEMBER AT 1PM.

Special Feature

ASHM, the Social Research and Allied Health Stream

By Mark Thompson

PLWHA Victoria had several delegates attend the 2004 Australasian Society for HIV Medicine conference. You will read Alan Strum's article on clinical and basic science in the following article. With my attendance at ASHM I concentrated on the social research and the allied health streams of the conference.

The first session attended after the opening ceremony dealt with the ever present issue of sexual risk. In three papers, sexual risk taking behaviour was examined in various groups of people in Sydney. In *Patterns of Sexual Risk Taking Over Time in the Health in Men Cohort*, L Mao examined HIV negative men who have been surveyed over a three year period (the HIM cohort). While a majority of the cohort did not consistently engage in sexual risk taking there continued to be a significant proportion who sporadically engaged in non-concordant unprotected anal intercourse. Similarly, in a study of young people in south east Sydney call *Summer Survival Sexual Health Survey* (Malpas G) 81% of young people between 16 and 25 had engaged in sexual intercourse but very few reported that they "always" used a condom during sexual intercourse, and reported an association with alcohol and drug use, unsafe sex and unwanted sex. The conclusion reached were that young people needed sex education material which included reference to drugs and alcohol as factors which influence decision-making, improve the capacity for schools and parents to address sexual health and improve access to general practitioners and sexual health services.

The other study was into a small but significant group of mostly young people, backpackers. In this study it was found that backpackers were a group who often engaged in sexual risk which they normally would not do in their home environment. Almost half of the backpackers surveyed had casual sex while on their trip and of those, 37% has not used a condom during their last sexual encounter.

All these studies, when considered together, indicate that interventions around safe sex, drugs and alcohol should not be restricted to the gay community, but should be carefully targeted to other key sections of the community that are vulnerable to the spread of STIs and HIV.

Another important presentation in this session was H, Worth's *A Dance of Death? Gay Men, Crystal Meth and Unsafe Sex,* which sought to get to the truth behind the sometimes hysterical reports around the use of crystal meth in the gay community and its connection with unsafe sex and the rise in HIV infection. In this paper, Worth argues that sexually adventurous gay men who use crystal meth as an adjunct to their sexual practice are aware of the dangers of drug use for sex and employ a range of strategies to ensure drug use remains controlled and pleasurable with sexual safety being a prime motivator.

A major theme to emerge from this conference was the re-evaluation of care models for PLWHA after several years of HAART and the development of services to cater for the side effects that anti-retroviral therapy carry with it.

One of the most exciting presentation was from RG Riley of The John Hunter Hospital, Newcastle. His presentation, *Refresh 2003: An Evaluation of Mainstream Support for a Retreat for Carers and People Living With HIV/AIDS* examined the development of a carers and plwha retreat in conjunction with a mainstream health provider, the Commonwealth Carer Respite Centre. This was the first time that a mainstream agency had collaborated with a non-government agency to fund a retreat for plwha. Besides the very successful retreat, outcomes for this project were a greater understanding of HIV issues by the Respite Centre

ASHM, the Social Research and Allied Health Stream

and the formation of an ongoing HIV Carers Support Group.

Another valuable partnership was outlined in J Thompson's presentation *The Villa,* where Sydney-based services, South West Inner City Housing, and ADAHPT, a NSW service for people with HIV and complex needs, collaborated with a number of other service and care agencies to help HIV positive people with cognitive impairment and complex needs to maintain secure accommodation. This project is in addition to the well-known *The Bridge*, which offers 24-hour care and support, however, *The Villa* offers much more flexible support with a view to maximising tenants independence and possibly independent living. This is similar in concept to the Berry Street project which is operated principally by The Afred Hospital.

It is clear from many of the papers presented that current practice around care, support and advocacy are being seriously reviewed to better serve HIV positive people. Here at People Living With HIV/AIDS Victoria, we will be monitoring and evaluating such work to ensure that the standards of care delivered in Victoria are the best possible.

Stay tuned for something special.
I hear the next treatment interactive event will be on Sunday December 5 at 1pm.

Vibe Cafe and Bar, 123 Smith St., Collingwood.

LET YOUR VOICE BE HEARD

Become involved, email us for:

The Scratching Post
This will be a page dedicated to what you have to say about anything you consider to be important. Pretty much anything goes on this page. However, inclusion of material is subject to editorial discretion and is not automatic. Please write a maximum of 200 words. To have your say email scratch@plwhavictoria.org.au

Personal stories
One of the best ways for people to learn about dealing with HIV is to listen to other people's stories. PLWHA Victoria will pay $50 for each story that is published in *Poslink.* Please be aware that not all stories will be published and therefore payment for a story is not guaranteed. Payment for stories can only be provided while funding is available. Funding is currently available for the next 2 issues of *Poslink*. Please write a maximum of 1000 words. Email your stories to stories@plwhavictoria.org.au

Future direction
We need to know what you would like us to write about. Examples of articles you may like us to write about could include topics that cover counselling issues, treatment issues or specific drug therapies, side effects, complementary therapies (please be specific), diet or political issues etc. Email your requests to ideas@plwhavictoria.org.au

Advocacy
Have you experienced problems with discrimination or access to health services? Call PLWHA Victoria on 03 9865 6772 and tell us what the problem is. We'll then assess if there is something we can do to fix the problem.

Special Feature
ASHM Clinical & Basic Science Report

By Alan Strum

The 16th Australasian Society for HIV Medicine Conference was held in Canberra this year. I have to say this is one of the most interesting conferences I have ever been to in my 12 years of attending numerous conferences. The level of local data presented from clinical trials and basic science was of international standard, providing a forum where learning and revision were excelled beyond expectation. One of the more interesting sessions was a review of antiviral therapy: when to start and what with, by Paul Sax from Boston. Paul presented an elegant review of clinical trial data released in the last 12 months with two very important take home points for lessons learnt in 2004:

Lesson 1: Triple nucleoside combinations that utilise abacavir & tenofovir or abacavir & ddI or ddI & tenofovir simply don't work.
Lesson 2: New data on ddI and tenofovir in combination with efavirenz shows that this combination does not work in antiviral naïve patients. However, it might be okay to use this combination in treatment experienced people.

I spoke with Paul about these combinations who advised the reason behind the treatment failures that have been occurring in these combinations is probably due to abacavir, tenofovir and ddI all developing resistance to HIV in the same way at codon 65 (the genetic position on an HIV enzyme). Therefore the virus seems to find it relatively easy to develop resistance to these combinations and appears to treat the 2 drugs like they are only one drug. Paul advised that fighting the virus with these drugs together does not appear to place enough selective pressure on the virus to prevent the development of resistance i.e. you are better off using drugs with different resistance profiles because the virus finds it difficult to develop resistance to drugs when they have diverse resistance pathways. Paul advised the data are very new and that the full data will be released at the upcoming ICAAC conference in November. [*Editor's note: See the article on 'poor study results for tenofovir with ddI' in the 'In The News' section of this issue for further information.*]

The following is a review of some key information presented at the conference.

Transmission of drug resistant virus in Australia
Ammarandond *et al* looked at the level of resistance in 299 new HIV infections in Sydney between 1992 and 2003. Results indicate no increase in protease inhibitor resistance (drugs like saquinavir) has occurred, a possible decrease in reverse transcriptase resistance (drugs like AZT or 3TC) may be occurring, while there was no change in resistance for NNRTIs (drugs like nevirapine).

Interleukin 2 Results
Two studies had interim data presented from the ongoing ESPRIT and SILCAAT studies investigating the actions of the immune modulating compound interleukin 2 (rIL-2). rIL-2 can stimulate CD4 (T-cell) production to help increase the CD4 cell count. Both of these studies have been recruiting for a number of years. It is a delight to see some data coming out of these comprehensive long term studies that will eventually tell us how rIL-2 might be used for people with HIV.

ESPRIT – enrolled 4150 patients initially with CD4 counts >300 on antiviral therapy. Patients were divided into an rIL-2 group receiving 7.5MIU twice daily for five days for three cycles over six months and a control group not receiving rIL-2. If required rIL-2 cycles were continued after six months to sustain the goal of an increase of 200 or more CD4 cells. This presentation focused on the identification of 'predictive factors' associated

Special Feature
ASHM Clinical & Basic Science Report

with obtaining the CD4 goal. 2090 people were randomised to receive rIL-2. 1,513 people completed three rIL-2 cycles with 12 month data available. 361 people had an increase of >200 CD4 cells at 12 months and had data available at 24 months for assessment. At 24 months, 199 of the 361 people continued to have a CD4 count increase greater than 200 (with or without additional rIL-2 cycles) while the remaining 162 people were not able to maintain the CD4 increase (with or without additional rIL-2 cycles). Predictive values associated with reaching the 200 CD4 cell increase were:

- a higher baseline CD4 count
- a shorter antiviral use
- a lower body mass index (low body weight ratio)
- people who receive more rIL-2

The investigators concluded this interim analysis confirms that rIL-2 does increase the number CD4 cells but responses remain very variable in this cohort, with a variety of factors contributing to a CD4 increase. rIL-2 cycling is the one factor we can proactively do something about. Assessment of the clinical benefit of IL-2 still requires several more years of follow-up.

SILCAAT – enrolled 1971 people (CD4 50-299 cells) on antiviral therapy who were randomised to receive 4.5MIU of rIL-2 twice daily for five days that were eight weeks apart for 6 cycles within 12 months, or more cycles as may be required to achieve a CD4 response. A control group did not receive rIL-2. The rIL-2 group was divided into two more groups according to CD4 counts and goals required:

1. 50-199 CD4 cell group goal was an increase of **125** cells (503 people)
2. 200-299 CD4 cell group goal was an increase of 175 cells (484 people).

12 month data was available for 838 people. 44% had achieved their CD4 goal by month 12. Positive predictors for achieving the CD4 goal at 12 months were:

- being male
- a lower BMI (low body weight ratio)
- a higher baseline CD4 count
- an undetectable viral load at the beginning of the study
- receiving more rIL-2

The investigators concluded that there was diverse exposure to rIL-2 in **year one of** the study (0-9 cycles) with more rIL-2 (6 or more cycles) being associated with a significant increase in CD4 cells for both CD4 groups.

The Alfred tenofovir study
Investigators at the Alfred hospital examined kidney function in 238 people who were taking tenofovir at their clinic from January 2001 to March 2004. Kidney toxicity was classified as a reduction in kidney function of more than 30% compared to kidney function prior to the commencement of tenofovir. Results show that 6.3% of people taking tenofovir develop kidney toxicity with or without Fanconi Syndrome while taking

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ASHM Clinical & Basic Science Report

tenofovir. Fanconi Syndrome is when the kidneys become 'leaky' leading to a loss of body salts and water. The kidney toxicity occurred around 10 months after starting tenofovir. Cessation of tenofovir allowed for kidney function to return to baseline values within 13-52 days. However 2 patients did not return to baseline values. [*Editor's note: This data is similar to the clinical experience of tenofovir published by Canadian investigators. This information is a reminder that it remains important for people on tenofovir to have regular kidney function tests done.*]

What are the pills doing?

Dr Darren Russell presented on the adverse effects of anti-HIV drugs. Most of these effects are those that are well published and discussed amongst doctors, researchers and pharmaceutical companies. Amongst the milieu of official adverse effects, Darren also presented information that brings these effects back to the human level; those adverse events that patients advise are of greatest concern to them:

Sexual dysfunction	29%
Sleep disorders	19%
Lipodystrophy	17%
Fatigue	17%
Flatulence & diarrhoea	12%
Dry skin	10%

84 week rosiglitazone results

The 48 week rosiglitazone results for the treatment of lipoatrophy (loss of facial fat) were presented at last years ASHM conference that showed very clearly that it doesn't help to regenerate lost fat tissue. At this years conference the 84 week results were presented which confirmed that rosiglitazone does not regenerate fat tissue in people with lipoatrophy.

NewFill: the Victorian experience

Ann Mijch presented results from the Alfred's NewFill study for lipoatrophy (facial fat wasting) showing that 20 of 27 people injected with the product had improvements in facial appearance out to 6 months. Psychological and emotional improvements were reported in those patients with self reported and photographic assessed improvements. Local pain, redness and swelling lasted for up around 2.4 days after the procedure but did not result in anyone withdrawing from the study.

Rosie Cummings from the Alfred presented on the social research of those participating in the NewFill study. Prior to the injections, people with lipoatrophy reported on their feelings about the affects lipoatrophy was having in their lives. Common themes included; stigmatisation, erosion of self image and self esteem, problems with social and sexual relations, anxiety, depression, social withdrawal and perception of unintentional disclosure. People were interviewed again 6 months after NewFill injections with some people indicating an increase in confidence, social interaction and the ability to go back to paid work. For others improvements were not quite so dramatic while for a few, the treatment did not reach their expectations, resulting in disappointment.

VIF revealed

Prof. Malim, Head of Infectious Diseases at King's College in London, presented information about cellular immunity to retroviruses. It turns out that human cells have quite an efficient natural immunity to viruses like HIV via the production of a molecule called APOBEC3G. APOBEC3G binds to HIV genetic material prior to integrating into the human DNA and changes it into a useless form that cannot cause infection. HOWEVER, HIV contains a gene called VIF which stands for 'viral infectivity factor'. When VIF is activated

the molecule it produces attaches to APOBEC3G rendering the complex to be digested by internal cellular mechanisms rather than allowing APOBEC3G to attach to the HIV gene. Prof. Malim presented an elegant piece of research showing that the addition of APOBEC3G to cells exposed to HIV prevents infection and proposed that APOBEC3G would be an excellent candidate for clinical research as a possible treatment for HIV.

The Alfred Lipodystrophy Clinic
HIV drugs have been shown to increase blood fats such as cholesterol and triglycerides in people with HIV and when combined with traditional risk factors such as age, sex, family history and smoking there is an increased risk of developing heart disease. Vanessa Carter *et al* provided information on the lipodystrophy clinic at the Alfred Hospital which has been set up to assess and address aspects of cardiovascular risk and physical manifestations of lipodystrophy (fat redistribution syndrome). 40 patients were followed from December 2001. In these patients, total cholesterol was lowered from 7.6 mmol/l to 6.3 mmol/l and triglyceride levels were reduced from 5.0 mmol/l to 3.4 mmmol/l. Reductions in cholesterol and triglyceride were achieved through medication and/or dietary changes. Medication changes included the introduction of fibrates, fish oil or statins with a last resort being suggested change to antiretroviral therapy. Risk factor reduction such as lowering the blood fats and stopping smoking appears to have reduced the 10 year risk for developing cardiovascular disease from moderate/high to low/moderate. Vanessa concluded that both dietary and pharmacological therapy play a role in reducing cardiovascular risk.

People can make a booking to be seen in the clinic by phoning 9276 6081.

Therapeutic use of marijuana
Andrea Fogarty *et al* presented a poster on data collected from the Positive Health cohort about the therapeutic and recreational uses of marijuana among 408 PLWHA in NSW and Victoria. 40.2% did not use marijuana, 33.3% reported recreational use only, 2.7% reported therapeutic use only, while 23.8% reported recreational and therapeutic use. Participants in the study reported perceived benefits of marijuana for reducing stress, counteracting weight loss, counteracting nausea and reducing pain.

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

In the news

By Alan Strum

Alan Strum
PLWHA Victoria
Treatments Policy
and Education
Co-ordinator

Poor study results for tenofovir with ddI

Information presented on *medscape.com* and recently published in *Antiviral Therapies* has shown that tenofovir combined with ddI may not be a good combination to use, resulting in a higher than expected number of people experiencing drug failure. The author presented interim results from a study of 36 people who had not taken treatment previously (antiviral naïve). Results from 26 people were available for evaluation. 14 people were taking tenofovir + ddI + efavirenz. 12 people were taking tenofovir + ddI + efavirenz + Kaletra. At 3 months, 42% of people taking the combination without Kaletra experienced virologic failure that was associated with resistance mutations to ddI, tenofovir and efavirenz. There was no virologic failure in those who were taking the combination with Kaletra. The author of this article advised that tenofovir + 3TC or ddI + 3TC or abacavir + 3TC would be better combinations to use instead of tenofovir + ddI. There were a number of theories put forward about why the combination performed so poorly. Some of these were:

- the initial viral load may have been too high for this combination to work effectively
- the combination contained drugs that the virus could develop resistance to easily (the drugs have a low genetic barrier to resistance)
- the combination may not have been potent enough without 3TC being present

[*Editor's note: PLWHA Victoria is encouraging people to see their doctor if they are taking this combination as their first HIV treatment for a review of their drugs. The number of people in the study is small. Small studies can represent aberrant information that might not be reflected in the general population. However, while the numbers are small, the data indicate that the virus did actually find it easy to develop resistance to this combination. Also, this study was in antiviral naïve patients. This data only applies to people who are on their first drug combination. More data from this study will be released at the ICAAC conference in November. These findings are in line with other clinical trials where triple nuke therapy also performed poorly that contained ddI + abacavir or tenofovir + abacavir as part of the combination. HIV can develop resistance to all of these drugs through the K65R mutation. When you combine the weight of the evidence from all of the studies, it would appear that using drugs with similar resistance pathways is not a good idea. It's like the two drugs combined are only acting as one drug. It is my understanding that from now on we will see less of abacavir, ddI or tenofovir being used together except in situations where there are no other options. Having said this, I have to admit that I remain unsure how this information applies to people who have resistance mutations to thymidine analogues (TAMS) like AZT and d4T.*]

References

- http://www.medscape.com/viewarticle/488779_print
- *Podzamczer et al.*, Early virological failure and occurence of resistance in naïve patients receiving tenofovir, didanosine and efavirenz., ABSTRACT 156, *Antiviral Therapy* 2004; 9:S172.

3 HIV drugs approved in Australia

April and July were busy months for HIV drug approvals in Australia. In April the protease inhibitor fos-amprenavir, a stronger version of amprenavir requiring fewer tablets, was approved by the Australian Drug Advisory Committee.

In July the protease inhibitors fos-amprenavir (Telzir) and atazanavir (Reyataz) were both approved for PBS listing (subsidised/free drug access) by the Pharmaceutical Benefits Advisory Committee along with the fusion/entry inhibitor enfuvirtide (T-20).

Unfortunately the new PBS listings will not be valid until December.

Hepatitis B drug receives PBS approval

A new Hepatitis B drug called Hepsera (adefovir) has been approved by the Pharmaceutical Benefits Advisory Committee for PBS listing in December. Hepsera will be available for people with chronic hepatitis B infection whose virus is resistant to the current anti-Hep B drug Zeffix. Hepsera is not cross resistant with Zeffix. In the Hepsera 483 study only 5.9% of people developed resistance to the drug in 3 years.

Gilead releases 24 week preliminary results

Gilead Sciences have released 24 week preliminary results from the open label 934 study comparing tenofovir + FTC + efavirenz to Combivir (ATZ+3TC) + efavirenz in 487 people who had not taken HIV drugs previously. The tenofovir/FTC group achieved better control of the virus with 88% having an undetectable viral

load compared to 80% in the Combivir group (less than 400 copies). There were also significantly fewer withdrawals in the tenofovir/FTC arm (3% vs 9%). The FDA has already approved a one tablet once a day combination pill of tenofovir with FTC called Truvada. This means that Truvada + efavirenz will only be two tablets once a day. Negotiations are proceeding to combine these three drugs into one tablet. Unfortunately the nucleoside analogue FTC has not yet been approved in Australia.

Erythromycin warning

Erythromycin is an antibiotic used for treating bacterial infections. Normally this drug is considered to be safe with few side effects. However, research from the USA has shown an increased risk of cardiac death in people who take erythromycin with drugs that inhibit the liver enzyme P-450 CYP3A. CYP3A is responsible for breaking down a number of drugs in the body as part of the elimination process. Drugs that inhibit this enzyme are some antidepressants, some antifungals and protease inhibitors. The investigators advised that concurrent use or erythromycin with CYP3A inhibiting drugs should be avoided.

More HCV trial results

A Spanish study has published results of a Hepatitis C (HCV) study in *AIDS*. The study recruited 95 HIV and HCV co-infected patients between 2001 and 2002 (32% female / 68% male). Patients were assigned to receive the antiviral drug ribavirin with either PegIntron (pegylated interferon) injections once a week or non-pegylated interferon 3 times a week. Patients with the difficult to treat HCV subtypes 1 or 4 were given treatment for 48 week while those with subtypes 2 or 3 were treated for 24 weeks. Sustained undetectable HCV viral loads beyond 24 weeks after cessation of treatment were higher in those taking pegylated interferon 44% vs 21%. For people with HCV subtype 1 or 4 the virological response for pegylated interferon was 38% vs 7% for non-pegylated interferon. For those with HCV subtypes 2 or 3 both interferon drugs worked equally well.

Sex drugs and HIV

Health officials in San Francisco have requested the US Food and Drug Administration to place warnings about increased risk for HIV transmission onto the product information and packages of sexual impotence drugs like Viagra. The health officials have advised there is now enough information available on recreational uses of the drugs that link them with crystal use, extended sexual activity and increased risk of HIV transmission.

Answers may be in the genes

Researchers at the US National Cancer Institute have discovered mechanisms for switching on HIV replication in latently infected cells. It is in latently infected cells where HIV can hide out for up to 60 years making it impossible to eradicate. The researchers have found that a compound called resveratrol creates the right environment in cells that allows HIV to start replicating. The HIV replication process eventually kills the infected cells thereby reducing the amount of infected cells in the body. It is thought that this type of method could help in either eliminating HIV from the body when used in conjunction with anti-HIV therapy, help to eliminate drug resistant virus, or help to reduce the risks of transmission by purging HIV from the genital tract. [*Editor's note: While this is interesting news, we have been disappointed previously with theories about eliminating HIV from the body. This research will require many years of development before we know what the realities will be. However, it is always nice to know that research like this is taking place.*]

Statins and HIV

Statins are drugs commonly used for inhibiting the production of cholesterol in the body. A Spanish study published in the *Journal of Experimental Medicine* has found that statins appear to inhibit the production of Rho guanosine triphosphatase. Rho is required for HIV to enter into cells and to leave cells. After proving that statins could protect cells from infection in test tubes, the researchers tested a statin in 6 HIV infected people (5 male / 1 female) who were not taking antiviral drugs. After one month on the statin there appeared to be a decrease in the viral load (-0.2 to - 0.9 log) and an associated increase in CD4 cells which returned to baseline for most people after stopping the statin. [*Editor's note: It will be interesting to see whether this can be repeated in larger studies. Apart from reducing cholesterol, statins also provide protection from cardiovascular events which is becoming more important for the HIV community.*]

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

Mitochondrial damage caused by HIV

A Spanish study investigated the effects of HIV on the health of mitochondria in 25 HIV positive people versus 25 HIV negative controls was recently published. Mitochondria are factories inside cells that produce energy. The HIV positive people had never taken antiviral drugs. The investigators took blood cells (PBMCs) from the participants and measured different components of the mitochondria. Blood cells from the HIV positive people contained 23% less mitochondrial genetic material (DNA) than the HIV negative controls which is indicative of damage. HIV also caused reductions in the complex III and complex IV mitochondrial building blocks along with increasing levels of glycerol-3-phosphate dehydrogenase that is associated with oxidative stress (damage to the cells). [Editor's note: This confirms our understanding of oxidative stress caused by HIV and may explain how HIV appears to speed up the aging process in some people. Taking antioxidants might help to slow down some of this damage. If you have any concerns, please see your HIV nutritionist for information on antioxidants.]

Acetyl-l-carnitine improves peripheral neuropathy

A British study of 21 people has shown that 1500mg twice daily of acetyl-l-carnitine can improve nerve pain and nerve structure in people who have developed peripheral neuropathy caused from HIV drugs. Peripheral neuropathy is usually associated with a tingling or burning sensation, or numbness in the hands or feet. HIV drugs can cause damage to nerve fibres in up to 66% of people. Nerve fibre density continued to improve or stabilise from 6 to 24 months of acetyl-l-carnitine treatment. Pain scores in the patients also improved greatly. Neuropathy symptoms worsened when treatment was withdrawn.

First month of therapy predictive of outcome

A joint UK and German study followed 482 people for 24 weeks who had commenced antiviral therapy. 73% had an undetectable viral load at 24 weeks. The research found a strong correlation with viral load after 4 weeks on therapy and those with undetectable viral loads at 24 weeks. The results are below.

Viral load at 4 weeks	% undetectable at 24 weeks
< 1000	84%
1001 – 10,000	61%
10,001 – 100,000	37%

Aim for below 20,000

The CHORUS cohort in the USA has been following thousands of HIV positive people for a number of years now. Investigators have recently released results of over 3000 people looking at factors associated with different viral load results for those on HIV therapy. Results from the first year showed that those with a viral load less than 400 had an increase in their CD4 count of 75 cells, while those with a viral load of 400 – 20,000 had an increase in their CD4 count of 13 cells, and those with a viral load > 20,000 had a reduction in their CD4 count of 23 cells. The 3 year results showed that people with a viral load between 400 and 20,000 were at no higher risk for clinical disease progression compared with the under 400s. [*Editor's note: This show's quite nicely the 'disconnect' that can occur in viral loads and CD4 counts for people who remain on therapy but who don't reach an undetectable viral load i.e. it's worth taking the drugs even if they don't appear to be working. However, continued use of protease inhibitors in the presence of a detectable viral load can result in more resistance mutations occurring.*]

IDUs may need to start HAART earlier

When following HIV treatment guidelines it is generally accepted that it is okay not to start treatment until the CD4 count falls to around 200 (depending on individual circumstances). Investigators from the AIDS Linked to Intravenous Experience (ALIVE) study in Baltimore gathered data from 920 HIV-negative injecting drug users (IDUs) and 583 HIV positive IDUs between 1997 and 2001. IDUs on highly active antiviral therapy (HAART) with CD4 counts above 350 had a similar death rate to the HIV negative controls while the death rate appeared to double for those who were between 200–350 and nearly quadrupled for those with less than 200 cells. The investigators suggest that it may be important to commence antiviral therapy when the CD4 count is above 350 for people who inject drugs.

Tenofovir and methadone

A drug interaction study of tenofovir with methadone in 14 people has shown that the two drugs do not interact with each other. The authors concluded that "tenofovir can be given as part of a once-daily antiviral regimen in patients receiving methadone maintenance therapy."
ref: medscape.com

Drug penetration into semen

Investigators in Paris have tested the blood and semen levels of a number of antivirals being used in 13 men whose treatment was failing them. T-20, Kaletra and ritonavir boosted amprenavir and saquinavir all failed to reach levels that can inhibit HIV in the testicles (semen). Indinavir appears to reach therapeutic levels while tenofovir levels were higher in the semen than in blood. While appropriate levels of efavirenz were reached in the blood, it could not be detected in the semen of 4 men. The investigators concluded that the inability for drugs to cross into testicles and semen creates an environment that can encourage virological drug failure. They advised it is "crucial to deliver adequate drug concentrations to all compartments where the virus can replicate in order to ensure the long-term efficacy of antiretroviral therapy and reduce the risk of sexually transmitted drug-resistant HIV strains."

WOMEN'S SECTION

MTC transmission timing dependant on HIV subtype in Africa

The rate of mother to child transmission of HIV varies from 16% to 50%. A study published in *AIDS* has shown that HIV-1 subtype C is more likely to be transmitted before birth (*in utero*), whereas subtypes A and D are mostly transmitted during birth (*intra partum*) or after birth (*post partum*). This has major implications for treatment prevention programs indicating that treatment to prevent transmission should commence earlier in populations with subtype C.

Nelfinavir and pregnancy

A Swiss study tested the levels of nelfinavir throughout pregnancy in 27 women. They found that nelfinavir levels in women are decreased by 35% during pregnancy. The drug levels become particularly low during the last trimester. Investigators noted that levels of nelfinavir could be increased to target levels when patients were encouraged to take the drug with food. It was recommended that all pregnant women have their drug levels tested and, if target levels are not reached, to increase the dose of nelfinavir from 1250mg twice daily to 1500mg twice daily.

Nelfinavir reduces oral contraception

New Orleans researchers examined the records of 2053 HIV positive women to assess who had become pregnant while taking oral contraception while receiving HIV care at their clinic. 11 women were identified as becoming pregnant while taking oral contraception. Women taking nelfinavir were more likely to become pregnant while those taking indinavir were less likely to become pregnant. This data confirms pharmacological data showing that nelfinavir reduced norethindrone by 18% and ethynyl estradiol by 47% while indinavir increases norethindrone by 26% and ethynyl estradiol by 24%. The investigators concluded that women taking nelfinavir should use additional or alternative contraceptive methods.

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Please tick ☐ **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.

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Telephone (optional) E-mail address (optional)

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6 Claremont Street
South Yarra VIC 3142
Tel: 03 9865 6772
Fax: 03 9804 7978

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