

POSITIVELY

August/September
2008

WESTLUND HOUSE
16 Gordon Street
ACTON ACT 2601

NAPWA Leadership Weekend

Michael, Mick and I landed in Sydney on the Friday afternoon and went to baggage carousel 5, which was the designated meeting point. Sure enough, as I sat there looking around, HIV positive people from all over Australia started gathering all around me. Those who knew each other met with big hugs and everyone introduced everyone to everyone with genuine delight. This was repeated when we picked up Kenn and the other conference delegates at Rydges in Sydney. The friendship, the goodwill, the honesty and the optimism in the air made for a dizzying concoction. For me, this was intensified when we were greeted at Wiseman's Ferry by an elder performing a smoking ceremony for us. I anticipated good things.

At the first meeting on Friday night, Michael Hurley, one of the facilitators, helped me to place myself in the picture, so to speak. The delegates were invited to self-select into one of three groups and stand with that group in the centre of the room. The groups were 'elder', 'adult', and 'youth'. While I have been positive for 22 years, I don't really consider myself to be particularly wise so I picked the 'adult' group, as did many people. When we looked over at the people in the 'youth' group, I understood that the label was not about age

but about experience of the virus and the community it engenders. There were many older people in that group who were relatively new to this community and considered themselves to be less experienced than others.

Over the weekend we were given the opportunity to explore what we can learn from, and what we can teach, each other. Once I knew what I could contribute to the weekend and what I could learn from those around me, the experience became a lot less daunting, by which I mean there were 39 people to meet and chat with over 2 days and I am a fairly solitary person. Also, it is easy to assume that everyone else in the room is up to speed on absolutely everything and can name all the non-nucleosides after 4 glasses of red wine. But I felt that my contribution was valid and valued, and I felt like I belonged there with those people; a good feeling.

On Sunday, the delegates were given the news that HIV is not a health priority on the government's agenda. I will let others discuss the Health Minister's odd behaviour but I will say this. Clearly, and doubtlessly, the funding implications of this government's approach to HIV are ugly, which is why the delegates spent Sunday brainstorming ways to tackle this emerging problem head on, as it were. After witnessing the free exchange of jolly good ideas that day, I am reassured that we, the

positive people of the ACT, are well prepared for the government's next few moves however devious they may be. Friends in every State and Territory are working with us.

Geoff P.

Three of us from the ACT recently attended a NAPWA Leadership Weekend that was held on 26th - 27th July. The weekend was facilitated by Michael Hurley from the Australian Research Centre in Sex, Health and Society.

The activities on the weekend consisted of interactive engagement and discussions around the topic of leadership. Some of the interesting topics covered were identifying leadership values and styles, leadership governance, advocacy and leadership presentations.

Our group also heard from many speakers who spoke about their own personal experiences of living with HIV and their involvement as volunteers and workers with various HIV organisations. I found it very inspiring to listen to the speakers and their different perspectives.

Personally I found the weekend to be very informative and I'm sure I will be able to use the knowledge that I gained to help me with my future involvement / work within the HIV sector.

MD

COMMUNITY-BASED
TREATMENT INFOLINE
FOR PEOPLE
LIVING WITH HIV

1800 817 713

MONDAY TO FRIDAY
2-7PM EST

 **treataware**
www.treataware.info

 **napwa**

Positively is a newsletter for HIV positive people, their carers, families and friends in Canberra and the surrounding areas.

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As you are all aware, POSITIVELY is a monthly publication for people living with HIV/AIDS in the ACT and surrounding districts. Currently we are looking for people to assist us with the publication e.g. writing groups. No experience is necessary as we will provide training in all aspects of publishing from writing articles through to the printing stage. If you can spare a couple of hours from time to time please drop into the office for a chat or give Marcus a call. Positively is a monthly publication produced within the ACT with funding from the ACT Dept of Health. Submissions for the next edition are due on **Wednesday 10 September 2008**. Opinions expressed in this publication do not necessarily reflect those of the editor, publisher, nor PLWHA ACT.

Positive Support Services in the ACT and surrounding areas

People Living With HIV/AIDS ACT

Provides support for HIV+ people in the ACT through a newsletter and links with other PLWHA organisations throughout Australia. We also provide individual support with advocacy and representation on health and other issues, and referral to other agencies. Phone 6257 4985

Positive Support Network

HIV+ people get together to offer support and share information. PSN is mostly a social occasion where people can share the experience of being HIV+ over a free meal, without the formality of a structured meeting. Dinner on alternate Tuesdays. Ph 6257 4985.

Positive Women's Group

The Positive Women's Group meets for social activities throughout the year. For information on the group's gatherings contact Marcus, Nada or Stephanie on 6257 2855 or 6257 4985

Trevor Daley Fund

The Fund provides assistance for people with HIV/AIDS who are experiencing financial hardship, for the part payment of bills, a treatments allowance and some other costs. Applications can be made to the TDF Committee by any service provider. For more information call the TDF on 6257 2855.

Counselling

Stephanie Buckle is the AIDS Action Council counsellor. Free consultation available to all HIV+ people, their partners, carers or significant others. Phone 6257 2855 to make an appointment.

Jane Keany is the counsellor for the ACT Division of General Practice HIV/AIDS Program, and offers subsidised counselling services for people infected with or affected by HIV, their significant others and people at risk of HIV infection. Jane is available at the Interchange General Practice. Phone 6257 3004 or 0402 222 408 to make an appointment

Health Maintenance and Treatments Information

All enquires to Marcus

Phone 6257 2855

Massage

Massages are available each Wednesday between 12.45pm and 4.15pm
Treatments are of ½ hour duration.
Appointments can be made by contacting the PLWHA ACT Office on 6257 4985.

Nutrition

Consultation with a dietician from The Canberra Hospital is available free at the Canberra Sexual Health Centre.
Appointments necessary. Phone Canberra Sexual Health on 6244 2184.

An HIV specialist nutritionist from Melbourne will be visiting quarterly. For further info contact Marcus on 6257 4985

Canberra Sexual Health Centre

Co-located with The Canberra Hospital. Free service available (no Medicare card is required) for testing and treatment of STIs, HIV clinic and counselling for issues such as safe sex, relationships and sexual functioning problems. Walk-in consultations available for urgent matters. Call on 6244 2184 to make an appointment.

Library

PLWHA and the AAC have an extensive range of books and videos for your enjoyment.

Educational books on HIV issues, cooking, Sci-Fi and general reading material just to name a few of the areas covered. If you would like to borrow any of them please see Lynn or Mandi at the AAC reception desk who will sign them out to you and explain the borrowing conditions. We also have a number of new books in the library this month.

Greater Southern Area Sexual Health and Hep C Service

Sexual Health Counsellor/Educators

Angela Trevaskis

Queanbeyan, Braidwood, Yarrowlumla Shire

Ph- 02-6298 9233 Mobile 0428 972 414

Aboriginal Sexual Health HIV/AIDS worker

Sharyn Medway

Ph 02-4827 3913 Mobile 0429 985 606

Sexual Health Nurses

Christine Taylor -

South Coast, Batemans Bay - Eden

Ph- 02-4476 2344 Mobile 0427 219 874

Shannon Woodward, Lee Constable

Queanbeyan-Goulburn Region

Ph- 02-6298 9213 mobile 042 789 3247

Margaret Trail

Albury 02 6058 1839

Robyn Ridley & Sally Anne Brennan

Wagga Wagga 02 6938 6492

Sally Daveron

Griffith 02 6966 9930

Clinical Nurse Consultant

Alison Kincaid Albury 02 6058 1831

Sexual Health Physician

Dr Katherine Turner

Ph 6298 9213

HIV/AIDS Related Programs Manager

Michael Bolton

Ph: 02 6923 5774

The Fine Print

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plwha.act@aidsaction.org.au

National Association of People Living with HIV/AIDS Leadership weekend

26 and 27 July 2008

I recently attended the above weekend on behalf of People Living with HIV/AIDS ACT at Wiseman's Ferry NSW. The weekend was facilitated by Michael Hurley from the Australian Research Centre in Sex, Health and Society.

The methods for the weekend which was attended by over 40 representatives from all States and Territories of Australia was interactive engaging with lots of discussions around the questions of 'what is leadership'.

There were eight workshops with short presentations in some sessions, but the weekend relied on active interaction and willingness to engage in dialogue and discussion with peers.

The eight workshops included

1. What is leadership – Identifying leadership values and styles.
2. Current contexts – Leadership governance and advocacy
3. Leadership and representation
4. What I have learnt along the way – working with / in organisations, playing different roles and advocacy.
5. An experimental workshop led by our facilitators.
6. How do I fit and how does the organisation influence my role
7. Local challenges – Leadership and solutions. Group work in various state and territory combinations
8. Reflective statements and what I have learnt.

The third workshop "Leadership and Representation" was very important to me as a member of PWHA ACT as well as job sharing as a representative on behalf of PLWHA on the AAC board and has a

representative on the Workers' Reference Group (WRG) of PLWHA ACT.

This workshop was about the differences between speaking your own experience and representing a population. What was the difference between speaking 'on behalf of others' and speaking 'about others'. How can difference in perspective amongst people living with HIV be included?

Discussions included people from the indigenous community, gay, bi, heterosexuals and women's groups. All with different agendas and approaches together with issues living with HIV.

One of the most important sayings that came up in some of the discussions was that if we were to be a leader in a HIV community we must learn to listen to carry the message to others.

Michael B

Darunavir and the risk of hepatitis

A warning has been issued by Tibotec, the manufacturers of Prezista (darunavir) regarding the risk of developing drug induced hepatitis while taking the treatment. Apparently, 0.5% of clinical trial participants who took a combination including darunavir (boosted with ritonavir) developed severe hepatotoxicity. Anyone with a history of liver-related complications such as hepatitis B or C are particularly susceptible, so appropriate tests prior to starting darunavir and regular monitoring while on the drug are vital to avoid developing any hepatotoxic reaction.

www.ashm.org.au

The Reading Writing Hotline

1300 6555 06

The Reading Writing Hotline is Australia's national telephone adult literacy and numeracy referral service. It is funded by the Australian Government Department of Education Science and Training (DEST) and managed by TAFE NSW Access and General Education Curriculum Centre.



SERVICES

The Reading writing Hotline can provide you with information on:


- Reading and Writing classes for adults in your local area
- Study by correspondence if you are unable to attend classes
- How to become a literacy volunteer
- Teaching and learning resources for adults
- Commonwealth-funded English as a second language programs for migrants
- Commonwealth-funded programs for Centrelink clients
- Literacy in the workplace

Telephone 1300 6555 06

E-mail at info@literacyline.edu.au

Is he thinking
what I'm
thinking?

www.thinkagain.com.au



Songs in the Blood Stories of Women Living with HIV

Globally, 50 percent of people living with HIV/AIDS are Women.

In Australia, it is 10 Percent.

Being part of a minority has shaped the experiences of HIV positive women. They are often isolated and their voices are rarely heard or understood.

The radio play *Songs in the Blood* tells the stories of 14 HIV positive and effected women who are mothers, partners, sisters, daughters and carers.

The women share their secrets and strengths, their pain and grief, as well as their joy and hopefulness. The stories are very real, challenging, engaging and celebratory.

Songs in the Blood was developed by the HIV Women's Project at Women's Health Statewide in Adelaide, South Australia. The project aims to promote the message that HIV/AIDS effects women too and raise awareness within the wider community of the experiences of these women as they live with HIV.

The powerful stories have been skilfully transformed into a radio play by writer Elisabeth Mansutti and production by Radio Adelaide.

The play was first broadcast on World AIDS Day 2007

We believe *Songs in the Blood* will touch the hearts of all who hear it.

We encourage the broad distribution of this CD to raise the profile of women who live with HIV. Please play it for your family, friends, work colleagues, classrooms and community centres.

Copies of the award winning radio play *Songs in the Blood* are now available from Women's Health Statewide, Adelaide. Please call 08 8239 9624 or email

pam.price@health.sa.gov.au . Limited copies are also available from People Living with HIV/AIDS ACT by calling 02 6257 4985

Attention Ladies

Would you like to Reclaim The Night?

"The philosophy of Reclaim The Night encourages grass roots participation in the organisation of events by as many women as possible. In this way it is able to draw together women from diverse backgrounds and experiences to work together in addressing issues of sexual violence against women and children."

If so please join us on 31st October 2008

We will be starting at Garema Place in the city

For more information please contact Lexxie at the AIDS Action Council on 6257 2855 or at Sex Worker Outreach Program on 62473443

Watch this space for further details

DIETICIAN'S CLINIC

Jenny MacDonald

will conduct a Dietician's Clinic
at the

AIDS ACTION COUNCIL
Westlund House
on

TUESDAY 9 September

Please call Mick or Marcus on 62574985 for further information and to make an appointment. Please bring your latest blood test results to the clinic.



HIV Balance

We have long known that ARV's (Antiretroviral drugs) have been a blessing to those with HIV as well as a curse. While mortality rates have plummeted, there has always been the trade-off of side effects such as lipodystrophy. Now that it has been 12 years since the drugs were made available, some of the long term effects are starting to be realised, such as increased risks of developing cardiovascular disease and diabetes.

The latest campaign to be launched by NAPWA and AFAO, and supported by the AIDS Action Council, is the *HIV Balance* campaign, and it is designed to look directly at the, positive changes PLWHA's can make in their lives to decrease the

negative impacts of their ARVs as well as other potentially beneficial changes that can help to improve overall well being and even the effectiveness of the ARVs.

The *HIV Balance* campaign is centred on six stories of people who are all living with HIV and the outcomes they had from making some positive, albeit often very difficult, changes for their health. The stories are uplifting and demonstrate that even small changes can make a huge difference, but they don't try to fool you into thinking that making these changes is easy and without their own challenges.

Living Positively will officially launch the campaign in a special colour edition that you can find here at PLWHA ACT. There are posters from the campaign that you will start to see around the

place, and we will have a different image featured in *Positively* over the next six issues.

So is that it, a few articles and some posters helping to hold up the walls of Westlund House? Well hopefully not! We would love to know what we can do to tie all of these things together. Come and have a chat to Marcus or Mick. Do you think that we should run groups on quitting smoking? What about starting Yoga or a cooking class here at Westlund House? If you don't feel like getting into the group thing, you could always talk to our wonderful counsellor Stephanie or anyone else from PLWHA or the Community Support Unit. We have heaps of resources on nutrition, our weekly massages, and you can always come and see Jennifer McDonald, nutritionist extraordinaire, when she visits the Council four or five times a year.



HIV made me realise
I had to treat my
body right. I started
to exercise once
a week, then twice.

The benefits quickly
became clear.

Managing HIV. It's all about balance.

For more information on balancing health and life,
contact your local PLWHA organisation or AIDS Council.



Nurse Philip

Dear Nurse Phillip.

I read an article in the June / July publication of Positively newsletter under the heading 'Living long term with HIV' that of those who have been HIV positive for more than 12 years, 41 percent could experience Peripheral Neuropathy. I have been living with peripheral neuropathy for many years and find relief by taking Omega 3 Fish Oil capsules three times a day. Can you give me some basic information on the cause of this condition?

Thank you

As you indicate, neuropathy is a condition that affects a significant number of HIV positive people. It is caused by damage to the peripheral nerves which are the nerves that lie outside the skull and spinal column (the central nerves are found within the skull and spinal column). Peripheral nerves extend from the brain and spinal cord to the internal organs and skin.

Damage to these nerves can occur in the absence of HIV. Other situations associated with neuropathy include smoking, diabetes, high alcohol intake, poor nutrition (particularly deficiencies of Vitamin B12 and Folate and high intake of Vitamin B6) and those taking any of a number of medications and drugs that can damage the nerves. It is therefore important in addressing peripheral neuropathy in HIV to exclude (or manage) these other possible causes of neuropathy.

The severity of peripheral neuropathy varies. It can range from a barely noticeable, intermittent numbness or sensitivity to touch through to deep, intense, unrelenting pain. Neuropathy is

usually experienced first in the feet and sometimes the hands; it often worsens over time if not effectively treated. Peripheral neuropathy is usually symmetrical in its distribution, that is, if it affects a part of the body, it is likely to affect the same part on the other side.

When it comes to neuropathy in HIV, the two main causes are the virus itself and some of the antiretroviral medications used to manage HIV infection. The neuropathic symptoms that result from these causes are similar. Other less common causes of neuropathy in HIV are opportunistic infections and auto immune problems. In the days before effective antiretroviral treatments, the main cause of peripheral neuropathy was HIV itself. Since antiretroviral medications have become widely used, this has decreased dramatically, as neuropathy is associated with low CD4 count and possibly high viral load.

When it comes to management, it is important first to address any underlying causes (such as smoking, diabetes, alcohol, nutrition and medications).

Some antiretroviral medications actually contribute to neuropathy; the main offenders are ddI, d4T and ddC. They are no longer widely used, mainly because of their tendency to affect the working of mitochondria (these are small structures inside cells that are responsible for much of the energy processing of the body). Impaired mitochondrial activity is associated with lipoatrophy (the loss of superficial fat deposits, particularly of the face and limbs). It is now thought that mitochondrial dysfunction also contributes to drug-related peripheral neuropathy.

The most obvious way of addressing antiretroviral-related peripheral neuropathy is to stop the suspect drugs. It is, however important to discuss this fully with your prescribing doctor before going ahead. There should be a plan for changing to another effective combination. For a small number of people who have problems with drug resistance or adverse reactions to potential alternative medications, this will not be easy. Most people find that medication change results in a slow resolution of their neuropathic symptoms over a number of weeks. This is more likely if there has been shorter duration of exposure to the medication and less severe symptoms. A small number report that the neuropathy can worsen for a few weeks before the subsequent improvement occurs. An antiretroviral regimen that successfully lowers the viral load and allows the CD4 count to increase (and doesn't contribute to neuropathy) should help minimise HIV-related nerve damage and reduce the symptoms.

Pain medications ranging from paracetamol and anti-inflammatories to opiates are chosen on the basis of the intensity of the pain and the response they provide. Some people, like yourself, find complementary therapies useful; other options that can help include certain amino acids, acupuncture and massage. Doctors sometimes prescribe anticonvulsants and antidepressant medication to help reduce the pain of neuropathy.

As there are so many factors that can contribute to neuropathy, it is advisable to spend some time with your doctor (and possibly an HIV-experienced neurologist) to work out a strategy for addressing this troublesome condition.

Brenda's Blenda

Having friends arrive at short notice last Sunday to see the latest exhibition at the Australian War Memorial, I decided to prepare a quick winter lunch, sausages and bean casserole. Very simple, tasty and filling.

You will need

- One tin of baked beans
- 1 small onion, finely chopped
- 1 can of tomatoes
- 2 strips of bacon cut into small pieces and grilled
- ½ teaspoon dried mixed herbs

Season with salt and pepper to your own liking

How to prepare

Grill sausages under a medium heat turning frequently until evenly brown, cool slightly, then cut into ½ inch pieces and place into a microwave container. Add beans, onions, tomatoes, bacon pieces and mixed herbs and salt and pepper to taste. Cover and cook in your microwave oven on high for around 5 minutes. Serve with lots of bread or hot buttered toast.

My hint to give the casserole an extra lift was to add several drops of hot black sauce. A side dish of mashed potatoes prepared in the microwave or stove top also go down a treat.

This will serve 4 people but can be divided into two meals. Any leftovers can be served on toast for breakfast the following day.

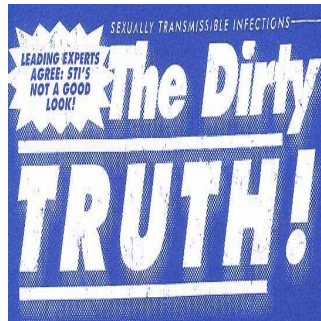
Enjoy

Brenda



The Dirty Truth

A new resource providing information on sexually transmissible infections (STIs) for HIV-positive men has just been released called "The Dirty TRUTH!".



It is in the form of a handy pocket-sized booklet and comes complete with explicit homoerotic imagery. Its use of actual pornography images and fun style is designed to engage the reader and make it easy for them to become more informed about STIs.

The booklet covers topics such as what STIs are, the interaction between HIV and other STIs, and getting a sexual health check.

Due to its use of sexually explicit material, the booklet has a R18+ rating and comes in a sealed wrapper.

The resource was developed by the Australian Federation of AIDS Organisations (AFAO). Executive Director of AFAO, Don Baxter, stresses how it is more important than ever to be informed about STIs and to have regular sexual health checks.

"STIs have been on the rise among gay men in Australia over the last few years. In fact, you are more likely to be exposed to STIs now than any time since the early 1980s, so regular sexual health checks are your best option."

The resource highlights that STIs can be more difficult to treat and be worse for men with HIV. "Regular sexual health checks are particularly important for HIV-positive men," Mr Baxter said, "Some STIs progress more quickly and can be more severe if you have HIV. Having some STIs can also increase your viral load if you are HIV positive, making passing on HIV more likely. Having some STIs can also make it easier to pass on and get HIV."

Robert Mitchell, President of the National Association of People Living with HIV/AIDS

(NAPWA) commends the production of this resource saying that it deals with the reality of STIs in a no-nonsense informative style. "It will encourage gay and HIV-positive men to remain vigilant around maintaining good sexual health. It encourages men to take care of their own sexual health, and to be informed so they can take care with sexual partners.

Taking a Look

"Taking A Look" is another new resource released by AFAO which provides useful safe sex information on the dynamics of HIV transmission.

The focus of this booklet will be on the basics of HIV transmission and specific areas where there is a 'mismatch' between knowledge and practices. There are also vital sections around anal and genital health - specifically on anal sex.

Within this resource, the problems surrounding serosorting (where men seek partners for unprotected sex based on HIV status) are also discussed. This topic is extremely important as unprotected sex with other assumed HIV-negative men may be one of the most significant causes of new HIV infections. This is because individuals who are seroconverting, or in the period of primary HIV infection, are likely to be the most infectious due to high viral load.

Importantly, this booklet will also cover other 'grey' areas of HIV transmission, including oral sex; 'nudging' (brief insertion); piercing; and the relationship between viral load and HIV transmission.



The resource cleverly uses non-realistic images of men having sex in order to emphasise the mechanics of HIV transmission and specific sexual acts (e.g. anal and oral sex,) and the basics of condom use.

Information taken from the <http://www.projectx.net.au>

Both resources are available from PLWHA ACT. Please phone for a copy to be sent to you or they can be picked up at the office during business hours.



This month's *Positive Living* is a special edition focusing on healthy living with HIV. If you're wondering how to make those small but essential lifestyle changes to keep healthy with HIV - getting regular exercise, eating well, cutting down on alcohol, cigarettes or recreational drugs - this issue has lots of information. The *HIV Balance* special issue was developed by the AFAO NAPWA Education Team.

Copies are available from PLWHA ACT—or via the web at www.napwa.org.au

COMING EVENTS

Wednesday 13.08.2008

Massage Clinic, PSN Lunch & Op-shop
 12.45 - 4.15pm

Tuesday 19.08.2008 6pm

Good bye to winter PSN BBQ and information session on the Treataware information line



Wednesday 20.08.2008

Massage Clinic, PSN Lunch & Op-shop
 12.45 - 4.15pm

Wednesday 27.08.2008

Massage Clinic, PSN Lunch & Op-shop
 12.45 - 4.15pm

Tuesday 2.09.2008

PSN Dinner 6pm Westlund House
Spring/Summer schedule re commences dinner every second fortnight unless other wise notified

Wednesday 3.09.2008

Massage Clinic, PSN Lunch & Op-shop
 12.45 - 4.15pm

Wednesday 10.09.2008

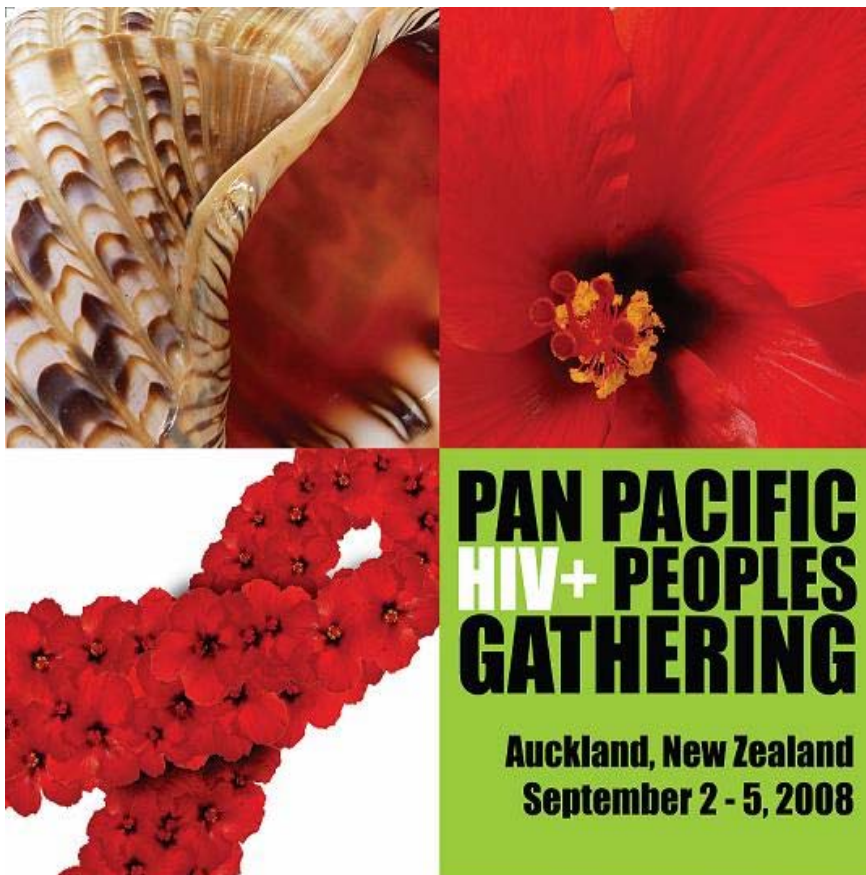
Massage Clinic, PSN Lunch & Op-shop
 12.45 - 4.15pm

Tuesday 16.09.2008

PSN Dinner 6pm Westlund House

Wednesday 17.09.2008

Massage Clinic, PSN Lunch & Op-shop
 12.45 - 4.15pm



**LET THE CALL GO OUT
 TO ALL THE POSITIVE
 PEOPLES OF THE PACIFIC**

www.panpacificiv.com

2.09.2008 to 5.09.2008

**Pan Pacific HIV+ Peoples Gathering
 New Zealand**

17.09.2008 to 20.09.2008

**20th Annual Australasian Society for
 HIV Medicine Conference — Perth**