



Positive Women

# Positive News



*Left to right: Dr Susan Paxton, Jan Waddell, Board Member Positive Women Inc. and a friend at the AGM of the Asia and Pacific Network of Positive people*

## August 2009

# **Diary Date**



## **Women's Retreat**

**16-19 April—2010**

# Coordinators Update

*Tena Koutou Katoa, Jambo, Hello, Talofa lava, Taloha ni, Halo olaketa, Bula vinaka, Kam na mai, La orana, Fakaalofa, Lahi atu, Malo lelei, Nabat, Zdravo, Ciao, Shalom, Saludo, Bonjour, Aman, Servus, Konnichi wa, Buenos Días, Nyob zoo, Torova, Namaste, Ci yi bak, Salaama.*

Hopefully you have managed to keep yourselves relatively safe from the winter colds and flus....not much longer of winter to go now....summer's just around the corner...

It's amazing how fast two months go by. Feels like we have just done one newsletter and then it's time to work on the next one.

We have some interesting events and stories to share with you in this edition. On page 8 one of our members tells about her long struggle to identify a life threatening condition called Adrenal Insufficiency which is not an uncommon complication of HIV, An interesting read and something some of you might want to follow up on for yourselves. I am sure many will be able to identify with the host of symptoms listed which we too often brush aside as we feel like we are being neurotic or 'bothering' the Dr's or specialist.

It is so useful to receive information like this, albeit somewhat distressing and even alarming, but sharing experiences with members is what Positive Women Inc. is all about.

We have some exciting news about the ability for people living with HIV to get life insurance. Something which has either been almost impossible or prohibitively expensive in the past. Read more about this on page 7. One of Positive Women Inc. members had a significant part to play in enabling this

to happen. Another indication of how much more empowered women are becoming.

Lots of news to read so I will stop...on behalf of Positive Women Inc. we wish you all well and don't hesitate to contact us with story ideas.

Kind regards Jane

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Thank you very much to the following companies for sponsoring Positive News



# Confidentiality...

One of the core values of Positive Women Inc. is that of *trust*.....

*Trust* that members can feel confident their confidentiality is respected and maintained at all times.

*Trust* that Positive Women Inc. will provide a *safe and supportive* environment for all it's members.

Any threats to this trust, especially in regards to breaches of confidentiality, are treated with the utmost concern.

Disclosing another members HIV status without their permission, can result in the offending member being unable to attend events such as the Women's Retreat, the Family Hui or any other

gathering of Positive Women Inc. members.

This is a very, very serious issue and will not be taken lightly if a complaint is made to Positive Women Inc.

If you have any concerns in this regard please contact the National Coordinator either by phone or email. Alternatively send an email to the Board of Positive Women Inc. at [boardpw@gmail.com](mailto:boardpw@gmail.com)

All complaints will be treated with sincerity, respectfully and in confidence,

Thank you for respecting the rights of others to their privacy and confidentiality.

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## Board Member Nominations

Two Positive Women Inc. Board members will have come to the end of their term and will be stepping down in April 2010.

This means we are now looking for nominations from members who are interested in putting their name forward to represent Positive Women Inc. as Board Members.

A Board member Job Description has been included with this mail out to all Positive Women Inc. members together with a nomination form.

All nominations need to be submitted to Positive Women Inc. by 2 November 2009.

Voting forms will be posted to Positive Women Inc. members in February



Voting for new Board Members will take place at the Positive Women Inc. AGM to be held on 16 April 2010.

People who are unable to attend the AGM are able to submit their votes by post which will need to reach Positive Women Inc. by the 2nd of April 2010.

Voting forms and return addressed envelopes will be sent to members in February.

If you are interested in being on the Board or wish to nominate someone else please complete and submit your nomination form.

## Positive Women Inc. TVC...

It's been nearly 18 months since Positive Women Inc. launched it's National Destigmatisation Campaign and buses are still driving around Auckland and Christchurch with the campaign posters!! That is just fantastic....

As part of the campaign Positive Women Inc. also had a Television commercial (TVC) produced. Thanks to

Ingrid Leary who produced this at virtually cost price. The problem has been getting TV air time but it looks like Ingrid may once again have come to the rescue as she continues to negotiate with TV3 for free air time So don't be surprised if you see some familiar faces looking back at you on TV3 some time soon.

## Annual Report 2008/09...

The Positive Women 2008/09 Annual report has been completed. As you will see, Positive Women Inc. once again achieved some amazing and worthwhile things during that period.

We want to thank all of our funders and sponsors for their continued support. As you will see even during this current economic down turn we have

been lucky to continue to receive enough funds to remain sustainable during a time when many organisations are having to close their doors.

Copies have been included with this mail out. Extra copies of the report are available from Positive Women Inc. on request.

## Disclosure experiences...

Disclosing the fact that one is living with HIV can be absolutely petrifying for some people. While disclosure is a very personal issue, there will be times when you may have to disclose, either to a potential partner, to children, to family and close friends or to health professionals.

Positive Women Inc. is looking to produce a disclosure resource which we would like to construct by using your stories and experiences .

Sharing stories, experiences and tips in this way will make the resource very real and relevant from the perspective of those living with HIV . Only those living with HIV really know the com-

plexities, frustrations, fears and anxieties which are involved when it comes to disclosure.

We are asking for you to send us your stories, experiences or tips which you are willing to share to help make up this resource. You don't need to provide your name. It can be totally anonymous.

We are also interested in hearing about experiences/stories from men or children and teens.

These can be sent either by post or email to Positive Women Inc.

We look forward to hearing from you and Thank you ....

# Marama's New Idea Article



*Marama, Maiinga and Tony Pala  
Member of Positive Women Inc., Founder and Kaiwhakahaere of INA Maori and  
Pacific Islands HIV/AIDS Foundation*

Exciting news in the Pala household with the announcement that the family of three will soon be four.....On behalf of Positive Women Inc. we wish to express our heartfelt joy and congratulations to Marama and Tony and to their extended whanau on their wonderful news.

Marama , a member of Positive Women Inc, and the founder and Kaiwhakahaere of the newly established INA Maori and Pacific Islands HIV/AIDS Foundation, was recently interviewed by New Idea Magazine.

For those of you who did not get to see the article, a photo copy has been included with this mail out. An interesting article with lots of information to help reduce the stigma and stereotypes associated with people living with HIV.

Marama also recently spoke at the Candle Light Memorial Service held in Hamilton and is a constant advocate for the rights of indigenous people living with HIV. We can be sure to hear and see much more of Marama in the years to come. Thank you Marama for taking a stand and congratulations once again.

# Life Insurance

Celebrations.....a new day is dawning. Those living with HIV have long lived with the discrimination of not being able to obtain life insurance cover. One insurance brokerage company challenged this while trying to get cover for a member of Positive Women Inc. with sensational results.

Yourlife & Associates is an insurance brokering firm offering professional brokering services to members of Positive Women Inc. as well as other HIV Support networks because as they claim "WE CAN get cover, no matter what the circumstances"!!

Risk Adviser Neil Peters explains. Whether or not you have been diagnosed with a disease or not, you never know what is around the corner. We may think "it will never happen to me" but we do die, sometimes prematurely, leaving family and loved ones behind. There are affordable products available to protect your family and loved ones from the unthinkable. These may be used for **mortgage repayment, day-to-day living expenses, raising children, protecting retirement savings** and also funeral expenses

As an HIV positive person you don't need a specialist HIV insurance broker. You need a broker who will treat you with the same dignity and respect as any body else. You need a broker who can provide the most suitable advice, coverage and protection for you and your family. Each case is treated on an individual basis. We are simply doing

our part to stop the stigma and misapprehension that is still prevalent in this day and age.

There is no 'one size fits all' cover package. Our specialist brokers will work specifically to meet the needs of each and every client. Working through a broker is easy and convenient as it enables a rapport to be established and you can be assured you will be talking with a person who has your best interests at heart.

All information is treated professionally and with utmost confidentiality.

Talking to a person they know personally and can trust.

A \$50 donation will be made to the Positive Women Inc. Torrens Fund for every successful application and successful referral from the Positive Women's Support Network.

The Torrens fund has been established to enable HIV+ children and Teens living in New Zealand to attend special camps in Australia arranged through the Sydney Children's hospital for HIV+ children/teens.

For more information contact Positive Women Inc. or contact ylife directly.

## Neil Peters

Risk Adviser

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# Adrenal Insufficiency

A members story .....

I am a Maori woman, living with HIV for the past 14 years. For a number of years now I have had various symptoms: muscle wasting, fat redistribution, fatigue, weight loss, muscle and joint aches particularly when stressed, difficulty with concentration/memory, slight depression, abdominal pain, night sweats, dizziness/light headedness at times, low blood pressure, low blood sugar and more recently, extreme muscle weakness and salt cravings.

Some of these symptoms have in part been somewhat ignored by me as I have never been able to get a definitive answer as to their cause from various health professionals when I have advised them of the symptoms. None have ever suggested further investigation other than my GP who suggested the abdominal pain may be stomach acidity/possible ulcer and prescribed losec. The pain dissipated at the time, but has returned on occasions since.

The GP also suggested the muscular and joint aches might be caused by fibromyalgia, a type of arthritis, but this was not followed up. I reported the aches, problems with concentration, memory, fatigue, night sweats, fat redistribution, and muscle wasting to my HIV Specialist, whose only suggestion was to change meds for the fat redistribution issue but other symptoms were not investigated any further. The muscle wasting/weight loss improved with the change in meds and improved viral load and CD4 count.

I previously thought most of my symptoms were just a result of living with HIV or the combined effects of medication, stress and possibly depression, so I just got on with it and the health professional appeared to not view them as serious either as they didn't suggest further investigation.

Sometimes I have felt as though I was being treated as "neurotic" by reporting "symptoms" here and there and then being somewhat fobbed off by medical professionals—either "it's just part of living with HIV, or it's nothing to do with the HIV or the meds".

Simply because I am living with HIV doesn't mean I am neurotically reporting every little complaint, nor am I contributing every ailment to being caused by HIV, but sometimes it is difficult to know what is and isn't related to HIV (apart from obvious things). I am merely taking an interest in my own health and trying to be proactive. On the other side, in my experience, (ie: when admitted to A & E 3 times over the last year), when medical professionals become aware of my HIV status, they sometimes tend to concentrate on that and to ignore the other symptoms I want investigated, which may or may not be HIV related and it has often been a battle to get these followed up.

With what I now have to tell you, I will now be even more proactive and pushy with the medical profession in future to get further testing done when I have "symptoms" and not let them tell me that they aren't really too much of an issue or don't need further investigation.

I recently had the traumatic experience of losing my first child who was stillborn at 20 weeks. Since then my "symptoms" became progressively worse. Dizziness, extreme fatigue, breathlessness, muscle weakness, muscle and joint aches and slight depression. Not putting this down to "normal" grief, I recently undertook some further research for myself on the internet and noted that these symptoms were all aligned with a disease called adrenal insufficiency.

The next time I went for my routine HIV blood tests which I have every 3 months, I ticked on the blood test form to also check my cortisol level (to do with adrenal functioning) just out of pure curiosity – not necessarily expecting to find that I did have a problem with my adrenal functioning.

I then found myself being telephoned by the HIV Specialist Nurse asking who had ordered this test, as they hadn't and nor had my GP, I advised that I had actually ticked the form myself as I seemed to have a lot of the symptoms.

I was then advised my cortisol level was very low (it was 5 when it is around 300-700 in a normal functioning person).

Further cortisol testing was urgently requested and I got the results the afternoon of the next day. This confirmed dangerously low cortisol and I was prescribed replacement cortisol treatment which I started that evening.

I spent the next two days in hospital as my blood pressure dropped rapidly. The dizziness increased and my asthma flared up. I now have to undergo further tests to determine the "cause" of my adrenal failure, further hormone testing to determine ongoing treatment and whether there are any further associated issues.

I have been informed that if I have an illness, severe nausea or a trauma, accident or even just a lot of exercise, I can go into acute adrenal distress which could be life threatening. I now need to wear a medical alert bracelet as if I go into adrenal distress I will most likely require an injection of cortisol steroid directly into the muscle to stop me from losing consciousness and cardiac failure/death occurring.

It is likely that having recently given birth plus the shock and trauma of having a stillborn child, escalated my symptoms, as my body simply couldn't cope, as I was not receiving the extra cortisol

that it would normally produce if my adrenal glands had been functioning properly. This could have led to me going into acute adrenal distress, - losing consciousness, coma and ultimately have been fatal.

I have since learned that pregnant women giving birth whom have adrenal insufficiency must have an IV drip to administer the extra cortisol required during labour normally; otherwise acute adrenal distress can occur.

*My key concern is that I discovered this health problem myself purely by accident, it was not diagnosed previously by a health professional.*

*I want to raise awareness in the HIV community and health profession about this often undiagnosed health issue and suggest we start screening for cortisol functions in HIV positive people regularly as a standard of care – I have found research from overseas which states this problem is often undiagnosed and not uncommon in those living with HIV.*

People with HIV are now living longer because of antiretroviral treatment, so it has become apparent we also need to start screening for common related illnesses associated with HIV, such as heart disease, diabetes and specific cancers - and as we have now discovered, adrenal insufficiency. I am having a meeting with the Infectious Diseases Unit to discuss this matter further in the next month.

If you want to know any further information about this condition, refer to HIV Spec/Endocrine specialist, but don't be surprised if they tell you it is a rare disease and uncommon in those living with HIV – refer to the research referenced on the next page and get your cortisol levels checked to be sure!!!

Hei konei ra

# What is Adrenal Insufficiency

The adrenal glands are located on top of each kidney and normally produce three classes of steroid hormones: glucocorticoids, mineralocorticoids, and androgens. Adrenal insufficiency occurs when the adrenal glands produce an insufficient amount of one or more of these classes of steroid hormones. Cortisol is the main glucocorticoid produced by the adrenal gland. Adrenocorticotropic hormone is made in the pituitary and stimulates the adrenal gland to produce cortisol.

These function to:

- Regulate blood sugar in the body and balance the effects of insulin
- Helps the body fight against infection
- Helps the body respond to stress
- Helps maintain blood pressure and cardiovascular function
- Helps slow the body's inflammatory response
- Helps regulate the metabolism of proteins, carbohydrates and fats
- Helps regulate appetite and weight
- Regulates the body's sodium and potassium levels
- Promotes the development of secondary sex characteristics such as underarm and pubic hair.
- These hormones may also be important for women's libido (sex drive)
- In men, most androgens (e.g. testosterone) are produced in the testes. Androgens made by the adrenal glands are not as important for normal sexual function.

Early detection of adrenal insufficiency can be difficult although treatment is usually successful once it is initiated.

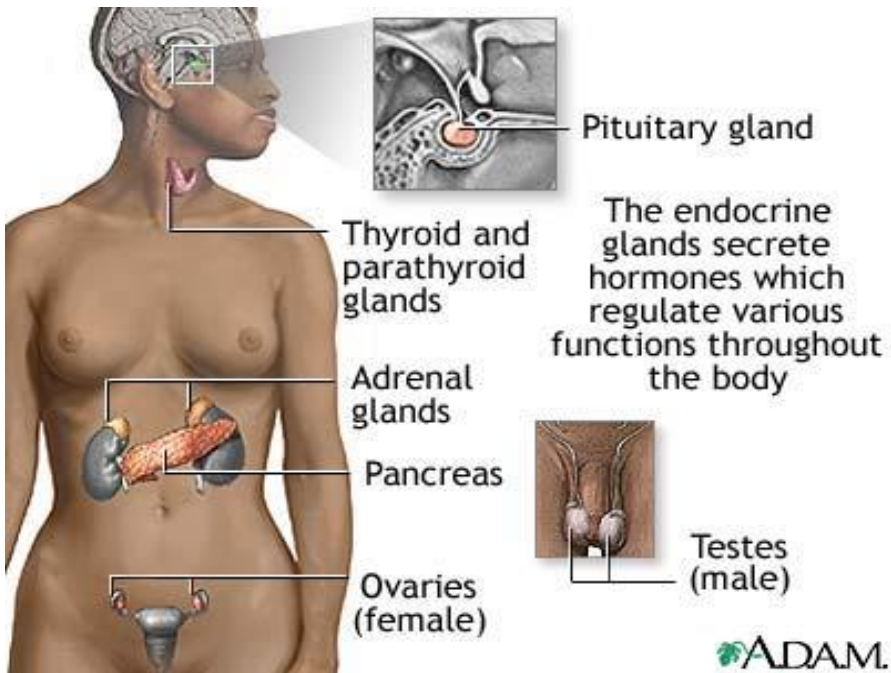
Treatment is tailored to the underlying cause and, in most cases, lifelong treatment is necessary. With appropriate treatment and a few added precautions, people with adrenal insufficiency can lead active lives and have a normal life expectancy

Cortisol levels are normally regulated by the hypothalamus and pituitary gland. Primary adrenal insufficiency, also known as Addison's disease, occurs when the adrenal glands cannot produce an adequate amount of hormones. In secondary adrenal insufficiency, an insufficient amount of ACTH is produced by the pituitary gland. In tertiary adrenal insufficiency, an insufficient amount of CRH is produced by the hypothalamus.

**The diagnosis** of adrenal insufficiency is a four part process: The blood cortisol level is measured, Other tests are usually needed to confirm the diagnosis of adrenal insufficiency, The level of the adrenal insufficiency is determined (primary versus secondary/tertiary), Once the level of the defect is known, further evaluation is done to determine the cause of the defect or to evaluate for other associated problems.

**Treatment** for those with inadequate adrenal gland function requires a daily dose of replacement cortisol steroid medication, every day for the rest of their lives, usually hydrocortisone, which is essential to help the body combat stress or recover from any shock, illness or infection e.g.: influenza, gastroenteritis, accident or operation.

When those things occur, the body normally would respond promptly by releasing additional hydrocortisone into the body at least for the first few



days to combat the effects of shock, stress or illness. This helps ward off the infection and aids prompt recovery. **If the adrenal glands for some reason (such as adrenal insufficiency cannot release the extra hydrocortisone, there is a danger of collapse, sever shock and even death, unless extra hydrocortisone is given.**

The extra hydrocortisone may be given by increasing the daily dose or where necessary by way of injection. As the person may be unable to inject themselves in some incidences i.e.: in case of accident or operation, it is imperative that they wear a medic alert bracelet to alert medical professionals of their condition, so they can administer an injection if the person has collapsed.

**Symptoms** of adrenal insufficiency include: weight loss, wasting, anorexia (appetite loss), muscle weakness, tremors (shaking), reduced endurance, fatigue, low blood pressure, low blood

sugar, changes in skin pigmentation i.e.: darkening of skin (on body or in mouth), dizziness, fainting, coldness, irritability, mood changes, lethargy, anxiety, restlessness, depression, emotional distress, reduced tolerance to emotional stress, reduced tolerance to physical stress, low blood sodium craving salty food, irregular menstrual periods, underarm hair loss (in women mainly), gastrointestinal disturbances (stomach upsets)

Symptoms of acute adrenal insufficiency (life threatening) – back pain (sudden penetrating lower back pain), Abdominal pain, Leg pain, sever vomiting, sever diarrhea, dehydration, low blood pressure, low blood sugar, high levels of potassium, collapse, loss of consciousness, coma –death.

For more information check:  
<http://www.ncbi.nlm.nih.gov/pubmed/11217816>.  
<http://journals.lww.com/ccmjournal/pages/articleviewer.aspx?ear=2002&issue=06000&article=00018&type=abstract>

# APN+ AGM Thailand



Jan Waddell, a Board Member of Positive Women Inc. recently represented New Zealand at the Annual General Meeting (AGM) of the Asia and Pacific Network of Positive People (APN+). Jan reported that:

Attending the APN+ AGM in Bangkok was a wonderful experience for me as a New Zealand woman living with HIV, and I was made most welcome by many who were both pleased and surprised at seeing a woman as the New Zealand delegate this year. It also gave me the opportunity to meet up with some I haven't seen since the Pan Pacific Gathering held in Auckland, Dr Susan Paxton being one of them.

Susan, as always gave a great presentation and what Susan had to say was a real eye opener for me, while I was aware of the situation in the Asian countries through e-mails from APN+, hearing the stories from the people themselves really brought it home to me. Susan shared with the delegates the findings of her studies regarding women living with HIV, this of course was of special interest to me, and she highlighted some of the challenges that they faced. Access to HIV services in Asia, testing, quality of services, etc, etc...I'm sure this is a part of APN+ we in New Zealand can help with.

Those who gave presentations on MSM and IDU did so with an amazing passion and commitment, one of those was a young man called Loon Gante from INP+. He spoke of the hopes of those living with HIV being torn apart because of stigma and discrimination. He certainly held every ones attention and is certainly a force to be reckoned with.

I felt very humbled by the whole experience. To listen to the country reports and to all those who are fighting everyday for the things we take for granted, free medication, free hospital care and easy access to them all seemed so unfair. I'm glad I was given the chance to see and hear first hand activist's such as Loon, men and women who show great acts of courage in so many different countries and who are fighting and working with no real resources and many from isolated areas. .



# Queen of the Whole Universe



*Miss Oz, (above wearing crown) winner of the 2009 Queen of the Whole Universe Pageant  
2nd place winner Miss Japan (below right)*

A night of sequin, glitter, high camp humour, mosaic colours and dubious fashion saw the crowning of Miss OZ, Barbi Prawn as the overall winner of the 2009 Queen of the Whole Universe Pageant, closely followed in 2nd place by Miss Japan, Kitty Tammy-Gucci, while Miss England, Annette Curtain was awarded 3rd place.

Head judge, Wellington Mayor Kerry Prendergast said "it was a very difficult decision as the standard of all five finalists was very high".

Unfortunately due to the costs of taking the production to Wellington, lower than expected ticket sales, and the folding of one of the events key sponsor, no funds were raised this year for HIV support networks. However it was a very successful night, which succeeded in once again drawing attention to HIV in New Zealand.

Positive Women Inc. would like to congratulate and thank the Queen of the Whole Universe organisers, sponsors and participants for once again pre-



senting a fun filled, entertaining event.

Next year, the 7th anniversary of Queen of the Whole Universe, will once again be held at THE EDGE on Saturday 06 November 2010.

# ARE YOU

The straight  
partner of a gay  
guy?



Feel alone?

Want someone to talk to?

Then why not join

- ♀ A new support group starting in Wellington
- ♀ Last Wednesday of the month @ 5.30pm
- ♀ First meeting 29 August 2009
- ♀ Confidentiality assured

*For more information email*

[spoggsupport@gmail.com](mailto:spoggsupport@gmail.com)



## Travel Insurance

Positive Women Inc. is able to help you get travel insurance at a very competitive price with no questions asked as to your HIV status.

This can all be done by email or phone. Call us for a quote

## HIV friendly Dr's & Dentists

Need to find a new Doctor (GP) or Dentist and are anxious about disclosing your HIV status? Give us a call and Positive Women Inc. will do the initial (anonymous) investigation for you.



## Straight Arrows Dinners

Last Thursday evening of the month

This social gathering is held on the last Thursday of each month from 6.30 pm to 8.30 pm in the central city. The Straight Arrows dinner is a chance for heterosexual HIV + people to come together for social support over a meal.

## Contact

**Positive Women Inc.**

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**For more information on any of the above**

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