



# HIV

## NEW ZEALAND

The Magazine for HIV+ People, their Carers and Supporters

Issue 3 • August 2013



**Dr. Massimo Giola**

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**Body Positive open in Wellington**

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# LETTER FROM THE EDITOR

“ Unless stigma is addressed in a mature manner in the management of HIV, diagnostic, preventive, treatment and care initiatives and interventions will always be playing ‘catch-up’ as stigma effects are subsequently revealed.

**Dr David Miller’s report commissioned by the Ministry of Health**  
*REVIEW OF SERVICES FOR PEOPLE LIVING WITH HIV IN NEW ZEALAND*

Welcome to our winter edition of HIV NZ. It’s 30 years since we were introduced to the HIV pandemic and whilst much is to be celebrated with the advances and progress that science and medicine have made there is much to be done yet. Jane Bruning’s article on stigma makes compelling reading and invites each one of us to personally reflect on our own experience.

Our positive personality in this edition is Marama Pala who reflects on her own experience of stigma and what she is currently doing about this. Her inspiring story sets a template of how we can combat stigma from within our own communities and encourages each and everyone of us to effect the changes we would like to see.

Changes have been effected in New Zealand over the last 30 years and Shaun Robinson’s article reflecting on the New Zealand response acknowledges those significant changes that have contributed to the New Zealand response . This can only be identified by world standards as a remarkable success, and contributing to

that success is our professional personality of the month – Massimo Giola. Italian born and educated Massimo and his partner moved to New Zealand for a better life and currently the Auckland District health Board Sexual Health Service employs Massimo’s expertise to Auckland clients. Apart from his professional credentials Massimo offers some of his spare time as a Board Member of the New Zealand AIDS Foundation.

Building on the New Zealand response, Body Positive has opened a Resource Centre in Wellington for our Members to gather information and share education. Clinical and non-clinical services will reflect what we offer from Body Positive in Auckland and replicate this in Wellington. This brings several years of ambition to fruition for those People living with HIV in the Wellington region. We are looking forward to working with our colleagues at the NZ AIDS Foundation there to build the New Zealand awareness and response to HIV.

**Bruce Kilmister**  
 CEO Body Positive Inc.

**World AIDS Day**  
**1 December 2013**  
**Volunteers Needed**

for street collections throughout New Zealand on Friday 29<sup>th</sup> November  
 Contact Maree on **0800 HIV LINE** or [maree@bodypositive.org.nz](mailto:maree@bodypositive.org.nz)





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# Dr. Massimo Giola

**M**assimo Giola has travelled a long and challenging road to find himself in New Zealand, but it is a journey that has paid off with big dividends, both professionally and personally. Massimo is now Sexual Health Registrar with the Auckland District Health Board, running sexual health clinics for both men and women. “We look after the whole spectrum of sexually transmissible infection,” says Massimo.

Originally from Milan, Massimo graduated from the University of Pavia, one of the most ancient universities in the world. The school of medicine is particularly renowned as one of the best in Italy.

Massimo graduated in 1991, and began to specialise in infectious diseases in 1996. “It was very clear to me right when I started medicine that I didn’t want to be a surgeon,” he says. “It’s just not for me. I felt out of place with surgical stuff, theatres and operations. I like infectious diseases because I thought it was the only field where you could actually cure someone rather than just looking after a chronic condition like most internal medicine.”

“I started with HIV & AIDS at that stage where it was pretty much a chronic, progressive, incurable disease. It was a pretty horrible time regarding HIV & AIDS. People were dying without any really effective treatment,” says Massimo.

“Luckily we got some effective treatments in the late 90’s so from then on we were quite advanced in our therapeutic options and possibilities”. Massimo did a PhD in Clinical Pharmacology from 2005 to 2008 working on the pharmacokinetics of antiretroviral drugs, the branch of pharmacology which studies how drugs are absorbed, metabolised and excreted from the human body.” It was quite interesting because all the antiretroviral drugs have been fast-tracked to approval for obvious reasons and most of them were approved without proper pharmacokinetic studies, like one dose fits all, irrespective of whether you are male, female, young, old, slim, obese, normal renal function or impaired renal function. All the pharmacokinetic work was basically done after marketing. People could not afford to wait. Long-term toxicity or long-term cancerogenic studies

were not done because it was so urgent,” says Massimo.

“We certainly discovered side-effects after marketing. The whole lypodystrophy problem came up years after Stavudine (Zerit) and Didanosine (Videx EC) were marketed and it was totally unexpected because there were no long-term toxicity studies for quite obvious reasons. People desperately needed an alternative to Zidovudine (Retrovir), and therefore Stavudine and Didanosine were marketed very soon after discovery and the first clinical trials,” Massimo says. “There was quite a lot of very basic pharmacology still to be done.”

“I started with HIV & AIDS at that stage where it was pretty much a chronic, progressive, incurable disease

In 2009 Massimo, who is openly gay, and his partner Andrea whom he met in 1993, decided to move from Italy to New Zealand. “We were both unhappy with our jobs in Italy. We weren’t happy with the fact that we could not have any recognition for our relationship as a gay couple. Today there is still no civil union in Italy.” Massimo was also tired of “the general rat-race of life in a big European city like Milan.” Commuting times, pollution, stress, and traffic congestion all took their toll on the couple. “We started looking around. I did my English language exam which was the precondition to possibly move and work as a doctor in an English speaking country and I sent some CV’s around and a few New Zealand hospitals were interested.” Invercargill hospital was the first one to offer Massimo a contract, so he moved in February

2009 and worked there for almost two years.

“I have fond memories of Invercargill. The hospital is very nice, the people are very friendly. I have made some friendships that I think will last for life there. After a while I started to have itchy feet and wanted to move somewhere else.”

“I was doing general medicine, a bit of everything really. As far as HIV goes I had probably six patients down there. As soon as I arrived I actually diagnosed a young guy with acute retroviral syndrome.”

Massimo decided to move to Tauranga because there was the possibility of working alongside another infectious diseases physician so he could get his vocational registration in order, and his specialty qualifications recognised. “I stayed in

Tauranga for 2½ years from Dec 2010 to June 2013. In the meantime Andrea retrained as a clinical coder, who basically translates medical information in codes that can be used for statistical funding purposes.” He now works in Hamilton for the Waikato District Health Board.

While living in Tauranga, Massimo realised he missed working specifically within the areas of HIV and sexual health and started to make inquiries about making the move to Auckland. Recently his efforts paid off and he began his new job with Auckland Sexual Health.

Massimo says sexual health is not a separate health specialty in Italy. “It is a bit of a grey zone between infectious diseases gynaecology, and dermatology for some historical reasons. If you are a man you tend to see an infectious disease physician if you have a sexual health problem.” When he was living in Varese, outside Milan, the town hadn’t ever had a sexual health clinic until it became compulsory by law that every town of that size should have one. “I actually set up the sexual health clinic in that town with a nurse because there was no one else willing to do it.”

Massimo was also elected to the board of the New Zealand AIDS Foundation in November 2012. “I see my membership as a way of providing some input. They hadn’t had a prescribing physician on the board for a long time.” He plans on staying involved with the Foundation “for as long as the members think my input is valuable. I would like to inspire the Foundation to be the hub of HIV research in New Zealand. I think we are already doing an amazing job, and with some key connections, we could really set up a very nice environment for the people of New Zealand living with HIV, and for the benefit of general biomedical research and knowledge.”

“We don’t realise living in New Zealand how lucky we are, and how well-placed we are compared to other countries in

many aspects, such as HIV prevention,” says Massimo. “We are doing very well actually, better than most.” He attributes this success to the early adoption of needle exchange programs, as well as the very strong focus on primary prevention, and condom use.

Massimo does see on-going challenges though. “The younger generation hasn’t seen people dying from AIDS. I have seen friends, people that were close to me, especially being a gay man and a doctor, get HIV and die. That remains in my memory very strongly. I can see how a guy who is now 18 or 19 hasn’t had that experience. HIV for those guys is an infection that you catch, you take some pills, and you don’t die from it. Of course they don’t realise you have to take your pills forever. You can still have side-effects from them. You can still have problems with the emergence of resistant viruses.”

In regards to a vaccine, Massimo believes “while we are moving in the right direction, I am a bit disillusioned regarding a vaccine.

I have been working in the field now for 20 years and I am still hearing the same thing about vaccines I used to hear 20 years ago. I don’t really see any progress. It is a peculiar area of research and you might have a totally unexpected breakthrough at any moment. It is very dependent on someone finding the right recipe at the right time, so I am not completely hopeless.”

What Massimo would really like to achieve in New Zealand would be “to have a collaborative group and a collaborative database so we could all share information and do some clinical research. Every centre has its own small database but they don’t talk to each other. There are ten patients here, 50 patients there, and perhaps a few hundred in the bigger centres. If we could have a common database and share the information we could really build up numbers, which would make sense from a research point of view, so if I could achieve that I would be satisfied.”

“We don’t realise living in New Zealand how lucky we are

## HIV Treatments Update 2013

Friday 27<sup>th</sup> September 2013  
Rendezvous Hotel, Auckland

By Bruce Kilmister  
*Body Positive Inc.*

Associate Professor Don Smith, Clinical Director of Sydney’s Albion Centre, will be the special guest speaker at this year’s HIV Treatments Update, to be held at the Rendezvous Hotel in Auckland on Friday 27<sup>th</sup> September. Don, a Kiwi by birth, will deliver two talks about his practice in Sydney, where over 3,000 people living with HIV attend for treatment. Recent HIV transmission rates of HIV in New South Wales have increased and bring pressure on all resources. Come and hear how the Australian experience is unfolding when Don delivers his talks.

On this side of the Tasman we haven’t heard of a mother-to-child transmission now for some years, but how are those children born with HIV coping now, especially as they mature in to adulthood? Dr Lesley Voss from Auckland’s Starship Hospital will talk about the transition of care for these children.

This year’s HIV Treatment Update seminar promises to bring more information and material for you. Increasing attendance over the years has caused us to move the seminar this year to the bigger facilities located at the Rendezvous Hotel on Mayoral Drive in Auckland.

**To register for this year’s seminar, simply visit [www.bodypositive.org.nz](http://www.bodypositive.org.nz) and complete the online registration form.**



World AIDS Day  
**Red Tie**  
Gala Dinner

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**Auckland  
Museum**

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**Saturday Evening  
30<sup>th</sup> November 2013**

For tickets or further information, contact  
Body Positive on 0800 HIV LINE or  
[gala@bodypositive.org.nz](mailto:gala@bodypositive.org.nz)



**+BODY POSITIVE** →

NEW ZEALAND  
Tinana Ora Aotearoa

My name is Jan and I'm HIV POSITIVE. You don't have to be PROMISCUOUS or an IDIOT to contract HIV, just unlucky. I contracted HIV from a NEEDLE, but not from using drugs as you may be thinking. I was a nurse and I was infected on the job while trying to dispose of a needle. The container for disposing used needles fell and instead of the needle going into the container, it went into my thumb. I knew my patient was HIV positive but I didn't panic. I took the preventative medicines and tried not to think about it, but they didn't work. I got sick, REALLY SICK and was diagnosed with HIV. I was then put on HIV DRUGS but they were so strong they were almost TOO MUCH TO BEAR. If this was what my life was going to be like, then I was ready to give up. My family's love and acceptance got me out of that DARK PLACE. Now I'm enjoying my retirement as best I can. I'm slower than I was and often I'm in a lot of PAIN, but I'm still the same person. I'm still Jan; the wife, the friend, the grandmother.



WAHINE  
KAHA

Positive Women



Free Phone: 0800 POZTIV (0800 769 848)  
www.positivewomen.co.nz  
email: positivewomen@xtra.co.nz

LOOK BEYOND THE STEREOTYPE  
THROUGH UNITY COMES STRENGTH  
Whakatauki — Tū kahikatea i te uru

# Stigma

By Jane Bruning  
Positive Women Inc.

It has been 30 years since the beginning of the HIV epidemic and the greatest barrier for people living with HIV continues to be stigma and discrimination. Regardless of which continent or culture, everywhere in the world this phenomenon is present and seems unable to evolve at the same pace as HIV medical advances.

## Defining Stigma

Attempts to define or provide a definition of stigma are complicated as stigma is applied to a vast selection of situations, with circumstances often being very different to each other. One definition identified by Goffman (1963) is that stigma is 'an attribute that is deeply discrediting', i.e. dirty, contagious or immoral, to which society uses to apportion blame or judgment to a person or group of people.

While stigma is socially constructed, the focus of stigma is often on the behaviours of those affected rather than the social construct of stigma. Looking at stigma from this perspective has resulted in stigma being seen as something in the stigmatised person, rather than a label that others attach to a person and where people are thought to be the thing they are labelled. i.e. a person is the HIV virus as opposed to a person who is living with HIV.

Link and Phelen (2001) believe stigma is identified when people distinguish and label human differences and place labels on undesirable characteristics generating negative stereotypes. The aim of stigma is to create some degree of separation between 'them' and 'us', creating a social status hierarchy which leads to unequal treatment or outcomes.

Stigmatised people are generally placed low in this hierarchy. As well as being stigmatised by society this hierarchical placement has an effect on those being stigmatised as their self-esteem and perceived opportunities are challenged, because they feel others look down on them.

Regardless of the impact of HIV on a person's life, most people describe an HIV diagnosis as something which drastically and irreversibly changes one's life. While this may affect many areas of their lives, the two main areas of concern are around disclosure and relationships, and both were inextricably linked with stigma. Secrecy and an attempt to keep HIV firmly separate from their everyday lives are seen as both enabling and constraining forms of protection for those living with HIV, which requires the need to develop coping strategies.

An HIV diagnosis abruptly displaces a person from everyday social order, forcing them to create a substitute reality so as to feel safe and to restore something of what has been lost. An HIV diagnosis robs a person from ever again feeling 'normal', and while most people like to consider themselves as unique or individual, there is also an underlying need to be accepted by society, and also by oneself, as normal.

The use of the word normal can be controversial in itself. After all what is normal? Just because someone has HIV does not mean they are not normal. Yet this is quite literally what lies at the core of stigma, because in reality people who are stigmatised, for whatever reason, are generally not seen to be normal. Hence the term 'normal' in the context of this article has been purposely used to highlight this inconsistency.

## Coping Strategies

Those living with stigma often adopt a sequence of coping

strategies. The fear of the potential and irreversible repercussions of disclosing one's HIV status can be so strong that for many, not telling anyone that they have HIV is the only means to normalcy. Trying to pass (as normal) is seen as a way to make life go on as if nothing has changed, even though everything has. This coping strategy is called passing. If diagnosed early, HIV is not physically apparent; there are no outward signs so it is easy to keep it a secret. By hiding that one has HIV and passing as normal, a person is able to create a protective world. However, an extreme example of passing would be denial, then continuing behaviours as if one does not have HIV and potentially infecting others.

While passing provides a protection and gives people a sense of control over their situation, the strain produced as a result of leading such a duplicitous and disassociated life can often lead to withdrawal from society. Many find the constant strain of trying to manage their secret challenging and draining. The constant lying and deceiving of those to whom they are closest: can create an enormous strain which inevitably affects people's personalities and behaviours. Those affected will often not talk about HIV in any context and many people often feel they are living a double life, behind a façade of being normal.

There is a conflicting train of thought which sees non-disclosure and passing as unconstructive and even dysfunctional, while others believe disclosure to be healthy and even therapeutic. There is literature which supports both positions. For many who have disclosed, they find they feel liberated and free, especially being free from the strains of needing to lie and make up stories in their attempts at passing, however there is also much evidence of the potential costs and disadvantages of disclosing for a person living with HIV.

People will evaluate the costs and benefits of disclosure. Often there are other considerations as well, such as the impact disclosure may have on children, family, especially elderly parents and friends. For some, the process of passing is used as an attempt at erasing HIV from their social world at a more fundamental level. By compartmentalising HIV and keeping HIV as something completely separated from their everyday awareness, it is seen as the best and often only way of being able to get on with their lives and of managing depression.

The second strategy, called covering, often occurs after or alongside passing. It is used when passing is generally no longer possible. The façade of being normal is dropped to some extent, but attempts are still made to conceal the true nature or origin of the illness. This phase involves a lot more lying, storytelling and deception, as it might become obvious to others that something is amiss. Fictitious ailments and excuses are created to cover the reality of what is truly happening. This creates considerable guilt, as well as moral and ethical dilemmas because of the need to lie, yet it is justified, because the truth is seen as a threat.

While covering effectively is an extension of passing, the main difference at the covering stage is that illness, or the fact something is wrong, is not so easy to be kept hidden and the fear others might guess what is wrong adds an extra level of anxiety.

Telling others about having HIV is largely determined by the need for support and the need to confide in someone as the burden of the secret becomes too great. This stage can be very

confronting and initial disclosure might involve only telling immediate family members such as one's partner, father, siblings or carefully selected close friends, in an attempt to find sympathetic others who will be accepting of the situation. Some may choose or feel the need to connect with others like themselves. This might involve joining a support network or just connecting with other people who are living with HIV, as there would be a level of acceptance and an opportunity for sharing information and providing support. The need to discuss one's situation to health professional and sexual partners are also factors in disclosing. This coping strategy is called 'seeking the own and the wise'. The 'own' being others (like themselves) living with HIV who share the stigma, and the 'wise' referring to health professionals and therapists, as these people are seen as safe.

Interestingly, many people living with HIV choose not to seek support networks as they have their own preconceived perceptions on what sort of person contracts HIV, and often feel they don't belong in such a group. Many also do not want to be associated with anything to do with HIV, for fear their own HIV might be discovered through association.

Despite the potential advantages of support, it appears seeking the own and the wise possesses significant contradictions between a preference for secrecy and the desire to disclose.

This is understandable as it is at the point of disclosure that there is a loss of control, either real or perceived, with no way to predict or control how others will react..

### Internalising Stigma

Internalised stigma or self-stigma is the process whereby the perceptions of stigma which are initially conceptualised externally by society, are accepted and turned inwards by the stigmatised person. This requires a level of acceptance by the stigmatised person that what is being said by society is true. This is then experienced in the form of negative self-image or negative self-worth, which may include feelings such as shame, guilt, being unclean and that one is a bad person.

Both the external and the internalisation of stigma ultimately affect all aspects of a person's life. Where the cause of the stigma is through a sexually transmitted disease such as HIV, it can have a detrimental effect on one's sexuality and also in negotiating relationships

Keeping the secret, through passing and covering, at least allows for the illusion of control and avoidance of discrimination.

The words stigma and discrimination are often used together, and while they do mean different things, discrimination is in fact the enactment of stigma. That is, the outwardly seen behaviours, such as verbal and physical abuse, and social distancing which includes withdrawing from people who are living with HIV often from a fear that transmission of the disease can be through casual contact or from being morally associated with someone who has HIV.

HIV-related stigma and discrimination is a result of fear and ignorance. We need to ensure all sectors of the New Zealand community receive appropriate and effective HIV awareness and prevention education, which will demystify HIV and subsequently reduce HIV stigma and discrimination.

“Stigma ultimately affects all aspects of a person's life

# The Jigsaw that Stops HIV

## A Comprehensive Approach

By Shaun Robinson, NZAF



New Zealand is one of the best countries in the world for keeping HIV at low levels, especially amongst men who have sex with men (MSM). Only three Scandinavian countries do better than us and in most countries the MSM epidemic is getting worse. How has NZ done it?

You'd expect me to say condoms-condoms-condoms! Continuous promotion of condoms for anal sex and a strong condom culture has been the most important factor, but it's far from the only one. Over 30 years a combination of actions have prevented the spread of HIV and responded to the needs it creates. Some of these key actions are so well established people forget their role. But it is the 'jigsaw' and mutual support of all its pieces that continues to make the difference.

Human rights and law reform have been critical. Marriage equality is one of the last in a long line of achievements that started with homosexual law reform, included the Human Rights Act and legalisation of needle exchanges and prostitution. Sex between men could be legally 'out' and therefore, safe sex could be talked about. Imagine 'Get it On' without homosexual law reform...not possible.

Then there is community building to create safer stronger peer communities that support people to look after each other. Bear Week, Pride and the Big Gay Out didn't always exist; this kind of community identity was built over many years.

Add to the mix advocacy for access to the best medications and care for those with HIV. Only a few short years ago no medications were subsidised; then a few were made available, but now NZ is right up there with access to government funded medications and care. In the last month Pharmac has agreed to

increase access to care for people with CD4 cell counts of 500 or less; another victory for all those who have advocated for the best possible care and support for people with HIV.

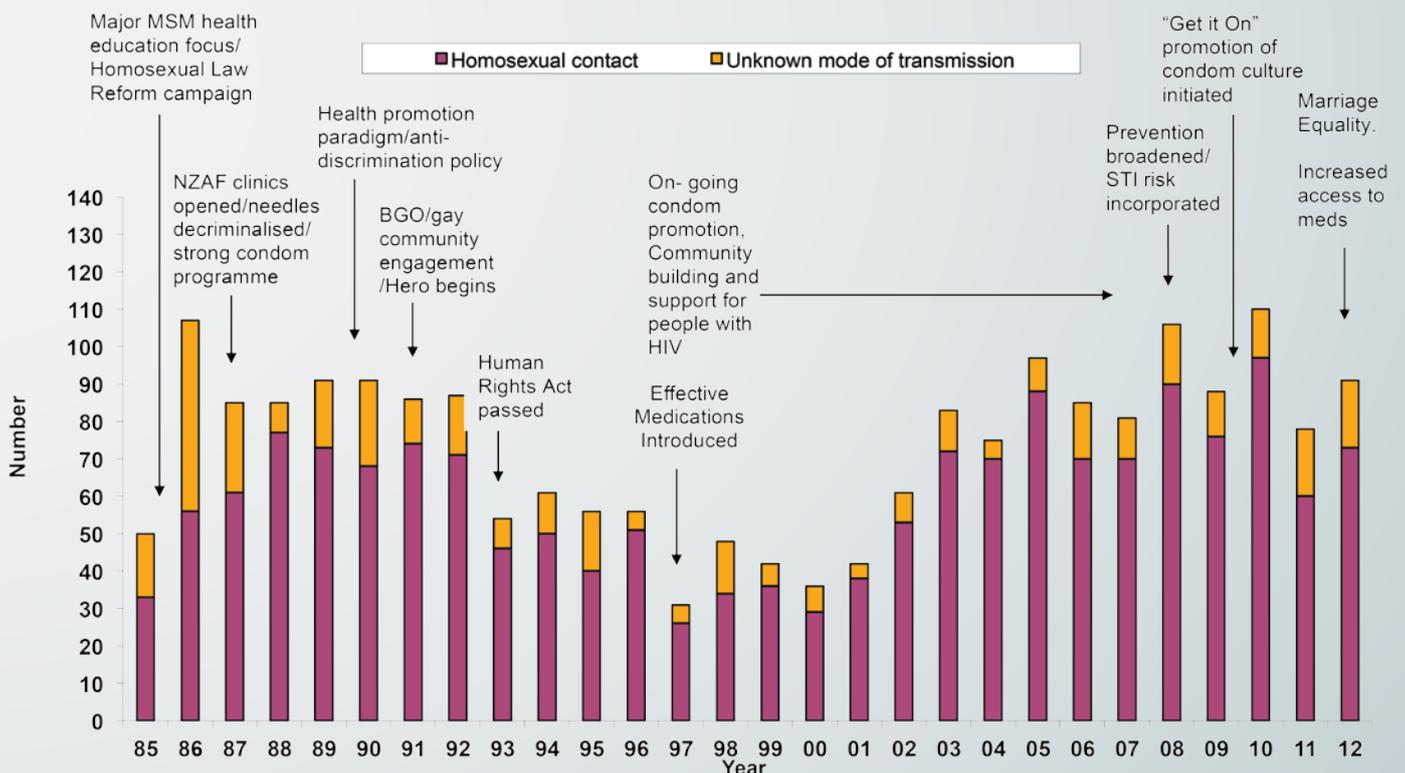
Of course we can't forget HIV testing. NZAF pioneered fast testing technology and testing in community settings. Our own testing has increased more than 700% to more than 2000 people a year since then, and testing over all in NZ has increased dramatically. Along with Body Positive, we model the use of innovative testing and agitate for the public health system to be more responsive in its HIV and STI testing.

Policy change and the legal environment have contributed better immigration policies, tests for pregnant women, decriminalisation of HIV and other important pieces of the jigsaw. Collectively we have strong networks between clinicians, community and government to assist progress.

So in NZ we benefit from a social and legal environment that is highly supportive of healthy attitudes to sex between men and diverse sexual identities; we have strong communities, good access to medications and clinical care and support, a sound base of testing - this is a good place to be out, proud and as sexually active as you choose. All of this would not have reduced HIV without high levels of condom use, but we wouldn't have a condom culture without the other factors.

We can be proud of our nation's comprehensive response to HIV! A jigsaw with more pieces than condoms! But neither you nor I can be complacent. Over 65 gay and bi-sexual men and 17 heterosexuals got HIV in NZ last year. There are still laws and attitudes to change, new clinical risks to manage, and yes, condoms to get on.

## Annual HIV Diagnoses for MSM & Major Prevention Activities



Data provided by AIDS Epidemiology Group, Department of Preventive and Social Medicine, University of Otago. Graph produced by Research, Analysis and Information Unit, New Zealand AIDS Foundation 2013.



# Positive Personality: Marama Pala

By Mark Garrison

**M**arama Pala can't stand still. A tireless activist and advocate for those living with HIV or AIDS, Marama has long been challenging the widespread stigma and discrimination surrounding HIV. Her primary focus and passion lies particularly within her own Māori community, and she travels the length and breadth of the country visiting marae, determined to change attitudes towards HIV. "I always say I turned a negative into a positive. Definitely I can't see my life being any different. Of course we all have that dream that we would love to not have it, but now that I have accepted it and had it for so long, I am doing what I can do to help other people with it."

## HIV in Māori communities

"A lot of the rural communities still think HIV is a death sentence and still think it is disease that affects only gay men," says Marama. "We have to re-educate people on a lot of areas that they would otherwise never be exposed to." To that end, she is constantly on the road. "I have had two weekends home in three months. Every weekend I was going somewhere talking about HIV."

One of the most pressing of the issues she is currently tackling is the fact "condom culture has completely missed the young Māori community. They know about condoms, they are taught about condoms in school but there is not much of an uptake on the condom culture at all; hence the highest amount of unwanted and unplanned pregnancies as well as STI's are Māori," Marama says. "It is very difficult to get a Māori male to use a condom."

Stigma and discrimination towards people living with HIV or AIDS however is what really drives Marama to put herself on the front lines of HIV prevention. "What happens in a Māori community is a lot us cannot afford to live by ourselves so we live with family. Moneywise it's the only way we can survive. You might have a family home where you could have up to ten or

15 people living in it. A lot of times one of them will have HIV and they are living in such close quarters that everyone knows all their business. So if all of a sudden they start taking medication the family will think 'what is wrong with you'? Often they will think you have cancer. There is a lot of fear of cancer as well."

## Experiencing fear and stigma

"We had two women die in the last year," Marama says. "One was Māori and one was a Pacific Islander. They didn't want to take their medication in case people saw them, and one of them, when she passed away, no one in her family knew she had HIV."

That's the kind of level of fear and stigma that we are fighting against." It is stories like these which motivate Marama to keep doing more to fight the fear surrounding the disease.

"They will always find some kind of superstitious reason for why becoming infected with HIV happened. I have heard everything. It has been part of my journey of stigma and discrimination. I have been told I only got it because of something my mother did. That's how they think. When you look at tackling stigma and discrimination within a community you have to be able to think like that as well. Religion has had a huge impact on it. Historically gay, bisexual and transgendered people were a completely normal part of society. There was no differentiation. The impact of religion turned it into an oddity or something that was wrong or bad when historically it never was. It was never considered different."

"We don't look at things in a straight line, we look at things in a unilateral way," says Marama. "When we talk to someone, we are talking to the people who lived before them and we are talking to the people in the future, so when you get into the kind of understanding of indigenous culture, you come to realise you are not just speaking to one person about HIV. My whole whānau and hapū got HIV. It didn't just infect me. It infected my mother,

“ A lot of the rural communities still think HIV is a death sentence and still think it is disease that affects only gay men

my father, my brother and sister, my first cousin and my aunts and uncles.”

“Society predicts what attitudes we take. I find it quite comical that there is such a huge amount of homophobia within the Māori community, yet there are not many marae you go to where there isn’t at least one Takatapui there. It is an insidious type of discrimination. It is more this fear of what people think about you or say about you. There is a little bit of superstition involved, like you got HIV because of something your grandmother did. It is not just Māori who believe that; it runs through all indigenous cultures. My friends in aboriginal Australia have stories of you are only gay because so and so did something in 1923.”

When Marama was diagnosed with HIV she felt like her life had been “completely devastated. It was a death sentence back then. I was 22 at the time.” The pain of her diagnosis was compounded by the fact that “in those days they strongly recommended that women didn’t have children because of the risk of passing the virus on, so basically I was told you have about ten years to live if you are lucky and don’t even think about having children. The biggest impact on my life was grieving those two things.”

“It took me a very long time. I was public. I was out with my status and I did speak up when I was 22 years old, but due to stigma and discrimination that actually didn’t help me. I became almost polarised within my community. No one wanted to have much to do with me after that because everyone knew my status.”

### **Increasing indigenous awareness and activism**

Marama says her activism was already there from the way she was brought up, and the environment she lived in. “I was brought up within an activist realm and environment. I suppose that when I got HIV they both kind of clashed.”

Despite the support of her family, Marama took things very slowly after her diagnosis. “For the first seven years before I got medication I had pretty much dealt with all the emotional side of it all. When medication came along it was a relief but I also had to change my life again because I wasn’t going to die,” she says. Once she was on medication Marama went back to school and completed two degrees, but her true calling emerged when she attended the 2005 Pan Pacific Regional AIDS Conference in Auckland.

“All the Māori who were there decided to hold a focus meeting and we all got together,” Marama remembers. “There were about 25 people and we identified a lot of the issues that weren’t getting met in the mainstream areas for Māori, particularly around women and children and the rise of STI transmissions within Māori populations. It was very bad. It still is now. It was actually to the point in one area out of all STI infections 80 per cent of them were Māori.” It was at this conference that she was first introduced to other activists such as Georgina Beyer, and Dr Clive Aspin.

In 2005 Marama became one of the founders of INA (Māori, Indigenous & Pacific Island HIV/AIDS Foundation) which became a charitable trust in 2008. “Over those three years we gathered a lot of support and met a lot of people. We ended up with quite a few people living with HIV on our board, as well as clinicians and epidemiologists. There was a wide range of people on the board who were very supportive. We spent time with our Māori communities up and down the country. We talked to political parties and gathered support from people. We knew we had to get people to come behind us. We ended up with 12 trustees and have been going strong ever since. INA provides a referral service. People contact us and we assess them and send

them to the right people who will be able to give them the support that they need.”

Another huge turning point for Marama occurred during a visit to her first international AIDS conference in 2006 in Toronto when she attended the international indigenous pre-conference. “I was a speaker there and I started to rally support and just get involved with the main players who were organising those pre-conferences. In 2008 we ended up in Mexico City and officially formed our organisation. We had our core group of HIV activists from Chile, Mexico, Bolivia, Guatemala, America, Canada, New Zealand and Australia.” Marama is now the female co-chair of the International Indigenous Working Group on HIV/AIDS.

“We started meeting regularly at different conferences and different indigenous environments and would always take the time and have a meeting. In 2010 we were in Vienna and finalised a strategic plan and a charter.”

“At every AIDS conference we have a pre-conference. Melbourne is next year and we have a pre-conference there. Between those conferences we do a lot of other work around supporting each country with advocacy. One of our successes is working with indigenous people in Chile. It used to be that if they gathered together to receive HIV education they would be arrested because it was illegal for indigenous people to congregate. The leader we have on our group was arrested and he went to prison. He got very sick. We did a lot of outside activism and put pressure on the government to get him released and he was. He is now the direct advisor to the Minister of Health on HIV in Chile.”

### **A collective voice**

“What happened when we formed our indigenous working group was we recognised that although we are different and have different beliefs and religions within our cultures, a lot of us have similarities. The Māori are very similar to the First Nations peoples of Northern Canada, particularly those who live in British Columbia. A lot of their beliefs are very Māori, and similar to ours. That’s kind of how we made that connection internationally and we support each other. It has been through the support of the working group that I have been able to get and do things here for Māori. It is almost like having an international NGO [non-governmental organisation]. We are able to come together and meet. We have Skype calls every two months but we physically see each other at least once or twice a year.”

Marama is quick to point out that her efforts are simply part of a collective voice. “I don’t think of it as just me. I think there is a whole whānau team behind me. I couldn’t do anything without my trustees. I don’t see it as a personal achievement. If something happens to me tomorrow someone else could easily do what I am doing. It is all about having that passion and having a voice and being not afraid to use it. I am not afraid to challenge my own culture, my own people, because some of their attitudes and behaviours are shocking.”

“I come from a family of very strong matriarchal women and not that long ago we were major landowners. From a woman’s perspective I’m not surprised that I am the way I am because I have generations of really strong women behind me. You are not just talking to me; you are talking to all those people in my past.”

“I faced a lot of discrimination in the 1990s and I challenged it a lot. Then I saw it happening to other people, and then I saw it is still happening today in 2013. That is what gives me the fire to speak up and keep being active and exposing that stuff.”

# International Indigenous Working Group on HIV & AIDS attends the United Nations Permanent Forum on Indigenous Issues

By Marama Pala  
INA Foundation

Bottom Left: Williams Morales IIWGHA Leader – Chile  
Bottom Right: Youth Caucus making a statement with recommendations at UNPFII

The International Indigenous Working Group on HIV & AIDS (IIWGHA) is the only international Indigenous group of its kind existing to build a unified voice for Indigenous peoples in a collective action against HIV & AIDS of which Aotearoa has two leaders involved – Dr Clive Aspin (Ngāti Maru) and Marama Pala (Ngātiawa) (Co-chair).

This year was the first year that IIWGHA leaders were able to attend the United Nations Permanent Forum on Indigenous Issues (UNPFII) in New York. This forum is the largest international gathering of Indigenous people globally who are specifically looking at issues of human rights.

The aim of IIWGHA attending this year was to raise and work towards the inclusion of HIV & AIDS as part of the Forum’s report, as indigenous people throughout the world continue to be adversely impacted by HIV.

“As a population at risk, working with forums such as UNPFII can only help shine the light on a dire situation,” says Marama Pala (Co-chair). “We urged the forum to listen to beginning the education that combats prejudice and discrimination for Indigenous people living with HIV, and to the role of culture in addressing the compound discrimination of racism, homophobia and transphobia faced by Indigenous people living with HIV, including women, children and youth. We asked them to dismantle stigma and discrimination associated to sex education, HIV & AIDS, STI’s, sexuality, sexual health, and reproductive rights, and be a part of decolonising our sexuality within our human rights commitments.”

Trevor Stratton (Coordinator of IIWGHA, Canada), who attended with three leaders, Williams Morales (Chile), Elisa Canqui (Bolivia) and Ken Clement (Canada) states, “We are convinced we made an impact at the forum but much more work and planning is needed in order to bring the full force of the UNPFII to address HIV & AIDS specifically.”

One of these plans was to hold a side event to the UNPFII titled “Working Together for Human Rights – Indigenous Peoples responding to HIV & AIDS and Sexual Health” 23 May 2013.

It was during this side event recommendations were made on how to have more of an impact at UNPFII, encompassing: ‘Getting to Zero’, ‘Harm Reduction’ and ‘Language and Culture’; emphasising the importance of safer sex materials; supporting whānau; disclosure; engaging harm reduction programs; more research on health disparities; implementation of cultural healing practices; and a better understanding of cultural sexual diversity within Indigenous communities.



# Body Positive Inc. Opens New Wellington Office

By Bruce Kilmister  
Body Positive Inc.

On Monday 15<sup>th</sup> July Body Positive opened a branch office in Wellington. The local Member of Parliament Grant Robertson officiated the ceremony and invited Body Positive's CEO Bruce Kilmister to lend a hand to cut the ribbon. This new Resource Centre as it is more aptly described is a place for People living with HIV to come and gather information, education, support, as well as a safe place to be in. It is the culmination of the Body Positive Board's ambitions for over five years now, as Wellington is the home of the second largest concentration of people living with HIV.

Ron Irvine has relocated from Auckland to take up the position of Wellington manager and says he is delighted to be returning to his hometown where he has his roots.

An amazing effort from volunteers and very generous support have provided almost everything the centre needed to commence operations. A kick-start grant from MAC AIDS made the project a reality, and shortly after the opening the new renovations were severely tested with two earthquakes that rocked the building, but engineers advise the foundations and structure are fine - so back to work. Services and facilities will replicate that which Body Positive offers from the Auckland head office and will be slowly rolled out.

Members are welcome to drop in and say hello when in the area. The Centre is located on level 2 at 55 Courtenay Place, Wellington. It sits above Burger King and is easily accessed by lift to the second floor. The telephone number is 04-801 5484.



Photos of Body Positive Wellington Opening courtesy of [www.gayexpress.co.nz](http://www.gayexpress.co.nz) - Photographer: Jeremy Green



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