Head on: a story of recovery against the odds

The Normal Heart: then and now

Massage: touching bodies and souls

Positive at the library

One man’s life with art

Where we speak for ourselves

Positive Life NSW the voice of people with HIV since 1988
NEW DIRECTIONS
THE 2011 POZHET ANNUAL WORKSHOP

Pozhet and Positive Life NSW invite you to join us for a day of information, discussion and support for heterosexual men and women with HIV, their partners, friends and family.

Where: Redfern (call for details)
When: Saturday, November 12
Time: 9.30am – 5.30pm (lunch provided)

- Latest on HIV treatments, transmission and having children
- Discussions with experts, male and female HIV workers
- Planning for building a healthy and fulfilling life
- Discussion groups: men, women, partners, family and friends
- A safe space to chat and explore issues in common

Scholarships available for regional NSW participants
Places limited. RSVP for catering before October 28.

Call Pozhet on 1800 812404 or email: pozhet@pozhet.org.au
Get in touch asap about childcare, scholarships, special needs.

The Heterosexual HIV/AIDS Service (Pozhet) is a NSW-wide service for heterosexual men and women living with HIV, their partners, friends and family

www.pozhet.org.au
Where we speak for ourselves

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Stephen Berry bungy-jumping in north Queensland, six years after diagnosis with PML. See page 15.
Hello and welcome to the latest Talkabout. I’ve loved working on this issue – it contains so many big-hearted stories.

This is my third Talkabout, so time to give you some background about myself! Way back in the days of hospital-based training, I became a registered nurse at RPA. But when I moved to London in the early ’80s, I made the switch into journalism, while keeping an interest in health. Magazines are my first love – growing up, I was an avid reader of the Women’s Weekly and Woman’s Day. In England, I worked on a popular feminist magazine, Spare Rib. Later I worked for Channel 4 television, as producer of the two lesbian and gay series, Out on Tuesday. Returning to Sydney in the 90s, I stayed in television as a producer at Film Australia. I also wrote for the Sydney Star Observer at that time. Then, I joined ninemsn and remained in the Web-publishing environment for over a decade.

Returning to working in print with Talkabout was initially strange but also familiar. I really enjoy the whole magazine production process, from commissioning writers to editing, selecting photos and writing headlines. And with this issue, I’ve been so pleased to have a number of readers approach me with ideas – ideas that you are about to read as finished articles! The backbone of this magazine is your stories and there is an open invitation for you to get in touch with your suggestions (editor@positive.life.org.au).

In this edition of Everyday Life, a number of people with HIV share their views and experiences of community. For the next issue (turn to page 7), I’m asking you to write in with stories of disclosure – who was the first person you told you were HIV positive, how did they react and how did you feel? Have you disclosed to anyone lately about your status? Does it get any easier with time?

Don’t forget that the magazine can be read online. This means you can share articles that you particularly like with your friends and family around the world. Just point them towards http://positivelife.org.au/talkabout.

Finally, please come and talk about Talkabout! We’re holding another readers meeting where you can discuss the magazine – what you like and what’s missing. Come and talk over nibbles at 6pm on Thursday October 6 at the NAPWA offices in Newtown (see ad on page 10). Bring your ideas for the future! If you can’t make it, your letters and emails are always very welcome. Susan Ardill

Facebook: Positive Life NSW
Twitter: @positivelifensw

Sonny Williams – our new CEO – is now on board and has settled into the swing of it all extremely well. Sonny has brought with him fresh perspectives and new ideas which have certainly revitalised and re-energised me. I am thoroughly enjoying working with him and look forward to the future. I would like to take this opportunity to thank Kathy Triffit for the tremendous work she did during her time as Acting CEO.

Preparations are underway for the Positive Life NSW Annual General Meeting, which will be held on Wednesday, November 23. As we now conduct elections for the Board by postal vote, full and distinguished members will have been sent the Board nomination form with the first notice of the AGM in early September. The ballot papers for the election of the Board along with the nominees’ supporting statements and information on how to vote will be sent with the second notice of the AGM in early November. Postal voting provides greater access for all members to participate in the election process, including those in rural and regional NSW, and I encourage you all to do so. If you want more information about the conduct of postal voting, you’ll find it in Schedule 1, Conduct of Postal Votes, in the Constitution, which is available on our website (http://positivelife.org.au).

A new feature of the AGM this year is that if a member desires to bring any business before a general meeting, they can do so. The process for this was outlined in the first notice of the AGM, in early September.

As I write this, the Board and staff are busy with end-of-year arrangements, including the preparation of the audit and Annual Report. We’ve also re-designed the Board Self-Evaluation survey. This will provide us with greater insight into how we’re operating and performing as a team and the areas we can improve on. Hedimo Santana has completed his term as staff representative on the Board and the staff have elected Lance Feeney as their new representative.

Sonny and I have attended two openings of new ‘homes’. The first was the opening of ACON in Elizabeth St and the second the opening of Coventry House in Melbourne, where PLWHA Victoria and Straight Arrows are co-located. The opening of Coventry House provided me with networking opportunities, a greater understanding of how PLWHA Victoria operates and the chance to meet with my fellow president, Paul Kidd.

If you’d like any further information about happenings with the Board, please contact me at president@positivelife.org.au. Malcolm Leech, President

Keeping you informed

A report on the latest goings-on at Positive Life from Malcolm Leech, President.
Welcome to Everyday Life, in which you, the readers, respond to a different talking point each issue. This time, I asked Talkabout readers to write about community – do you feel part of one or not?

I posed these questions to help you get started writing: ‘Community’ is a ubiquitous buzzword. Has it become an empty word or do you feel a sense of genuine community in your life? Where is your community – in your neighbourhood, at your sports club, in a bar, online? Who is your community – does it include other people living with HIV? Are you part of more than one community? How did you find and join a community? Tell us about your community life.

The answers are sometimes unexpected. See the box on page 7 for next issue’s talking point, a subject everyone with HIV can relate to – and get writing! Susan

Thriving in community

I live out in the bush near Nimbin. A refugee from Melbourne/Sydney, I moved to the Northern Rivers in 1992. The idea of community is alive and thriving in my world. I’ve always been a joiner, attracted to one community/tribe or another. When newly positive in Sydney in 1984, I helped start the first self-help HIV support group called Body Positive, but that’s another story.

I’m connected to at least three different if overlapping communities these days. And I’m so thankful that I’m fully supported to be out with my HIV status in all of them. Mind you, I’ve always taken my time in coming out as positive, choosing the people, the community and the time according to my needs.

My first community is my home. It’s pretty unusual, rare even. And certainly there’s nowhere else I’d rather be. I
live on a 54-hectare intentional land-sharing community. We are a Radical Faery Sanctuary. There are similar communities in the US and one in Europe. Yes – a queer hippy commune! And of course it’s called Faeryland. I’m the only positive guy among seven fulltime gay residents. We’ve been established for eight years now. I’ve always been out positive both with the other full-time residents and the many visitors and I feel fully safe and supported in my home.

We all live together in a shared house but each have a separate bedroom cabin space. We eat together every evening. We try to live as sustainably as possible. We’ve created a communal home. We are a queer family. We see ourselves as stewards for this property we purchased together.

We believe it’s very important in all our relating to be as open/honest/heartfelt as possible. It’s not always easy. We acknowledge that harmony/conflict is very much part of living in community. And we regularly do work to learn new processes and practise better communication and deal with conflict. My experience is that we do this well and have grown enormously in ourselves and as a community over the last eight years and we are very committed, I reckon.

We are also a sanctuary for the faery/queer tribe of this world – quite a big thing to be offering. Those who come to spend time with us can throw up some rich and rewarding challenges for us individually and as a group and no doubt we do the same for them. We do our best. We are not a therapeutic community. Those seeking sanctuary here (for a few days to much longer) are asked to let us know before visiting what draws them to us. We try to be clear with them about what we can offer: a healing space to do some more of their own inner work and a chance to experience a living community.

At Faeryland we’re always doing stuff together. We regularly work on the land. And yes, we talk a lot too! Weekly heart circles and business meetings, working bees, planning meetings and intensive weekends every few months. We also do community fundraising, political work/activism and organise fun things for our larger tribe, such as Glitterballs and community lunches. We couldn’t survive without being supported and held by a large circle of queer and straight friends, both locally and beyond, in Australia and overseas.

I’m one of your longterm survivors. I was first tested in 1984! And I attribute that I’m still alive very much to living in such a healthy, supportive space in the country. But I do have a life outside our little piece of heaven. Two other communities are very important to me. Next is my Tropical Fruits tribe. (I use community/tribe interchangeably). The Fruits is a regional LGBT social and support organisation and my Fruity family is very important to me. I’ve been on and off the management committee the whole time I’ve lived up here (a joiner, as I said!) We have a clubhouse, the Fruitbowl in Lismore, and I’m there most weeks helping out, catching up, getting hugs and sharing stories or doing my latest project, collecting our queer history. We do lots of stuff. All with volunteers. We work closely with the local ACON branch. In August the Fruits held our annual Fairday and I was there at our Faeryland community stall doing tarot readings, bedazzling passers-by and selling faercakes, surrounded by my bigger Fruity community. It was yummy.

The third community I want to claim is my local village, Nimbin. I’ve volunteered at the Neighbourhood Centre for years. (There’s that joining thing again!) The centre is my home in town. And my involvement has connected me to an amazingly rich group of people. I think I was always meant to live in a village. A stroll up the street to do some shopping can take hours as there is so much gossip to catch up on and so many coffee shops to sit in! Again, more hugs and a listening ear. Again, I feel fully supported as a positive gay man.

There are many other communities I belong to. Too many to mention now. But I must finally mention the small group of HIV positive friends living in the Northern Rivers. I don’t connect with them in any formal way any more, but when we see each other it’s always a chance to check in: how are we doing living with the virus so long? Our drug and side effect stories, the latest health scare, stories from the past, who’s not well? Amazement, sometimes, that our little community is still alive…

So that’s my community story. It’s not an empty word for me. My communities have kept me alive and thriving for so long and will do so till I die. Teacosy/Ian

Ozfaeries: http://www.ozfaeries.com

A stronger person

When I reflect on the meaning of community, the following comes to mind:

W

For companionship
C

For opportunities
O

For members
M

For mutual
R

For unity
N

For negotiation
G

For interests
I

For trust – and
Y

For yes, fun!

Like many people living with HIV, I belong to the HIV-positive community in all its diversity. I am a woman, mother, daughter, friend, peer support worker, board member and positive speaker. When I mention a community, I envisage a sense of

Katherine Leane (left) and Pam Price from the HIV Positive Women’s Program at the 2010 Adelaide launch of Body of Knowledge (created by Positive Women Victoria).
belonging to a group of like-minded people – and if not always like-minded, then people who share similar values to the list above.

For me, whether it's a board, women's network, school, sports club or social group, it's that sense of being connected and feeling like you have a place where you not only belong but can be yourself. Communities consist of many different personalities and egos. It's not always possible to like everyone, with our different political views, range of ages, life experiences and sometimes prejudices. Yet we all need to belong or feel accepted somewhere and I believe there is a place and space for everyone.

As a child I belonged to the Brownie and Girl Guide movement. As a primary student I belonged to a school community and the Catholic church. Then as a teenager, my focus shifted to rock music, fashion and peers. In early adulthood I was a uni student, attracted to people who used drugs, and then was in the workforce. When I became a parent to two children, I belonged to many different communities – neighbourhood watch, childcare and school.

In hindsight I can see that part of my confidence and self-esteem came from the sense of belonging I felt. That willingness to take a risk and put myself out there, believing my ideas and thoughts mattered the same as anyone else's, was a driving force. I strongly believed that to be part of a community meant you had to give as well as receive and sometimes that meant taking risks. Sometimes it means others will judge you, but the lesson I've learnt is that life is about taking risks and this is something we can all do.

In the early days of my HIV diagnosis I decided I could no longer live with layers of secrets. The communities I decided to engage with had to accept me for the person I was and not for who they wanted me to be. Once I lived by this philosophy, I was able to face many challenges. Not only did my resilience grow, so did my ability to be open to others regardless of whether they understood my lifestyle situation or not. Today I appreciate all the groups and communities I have been part of because they have each contributed to who I am and have, I believe, made me a stronger person, able to face the many challenges life throws at us. Katherine

Communities

As a youngster growing up on the outskirts of Sydney in the '50s and '60s, communities were safety zones in areas that were just starting to develop (like Sylvania, where I was born). Everybody kept an eye on everybody else and you often lived as much in your neighbour's home as in your own. People were always available for a chat, baking was shared around the neighbourhood, everyone knew your dog and you knew everyone's name. Religion, whether you practised just to be part of the community (as my parents did) or for actual reasons of belief, didn't seem to really matter. When there was a birth or a marriage, everyone came to visit. When somebody died, everybody mourned. It was close and nurturing. However, it had its drawbacks. Perhaps everybody knew a little too much about everybody else. When my mother deserted the family home, I remember not so much what was said as what wasn't said, as if it had been expected.

My next community was boarding school – very Catholic and, I have to say, very fulfilling. I had a large circle of friends. However, the wide divide between city boys and country boys (it was an agricultural college) became evident when I left school and found that I didn't continue contact with any of them.

After leaving school I moved to a very hectic straight community, a large group of friends who I socialised with pretty well every weekend. We dined out, drank way too much, went to far too many concerts and were heavily involved in each other's lives – again, not necessarily a good thing. When I made a large move to another state, the friendships seemed to drift apart. I guess the glue that held the group together wasn't that strong after all.

Moving into the gay community was a big leap for me and it was one of the strongest communities I have lived in. Let's face it, I lived gay. I drank in gay pubs (way too much), danced in gay nightclubs (way, way too much), read gay media, shopped in gay shops, went to gay doctors and solicitors, lived for Mardi Gras and Sleaze Ball and had lots and lots and lots of gay sex (never too much!) Life in the ghetto was just one big 'gay'. Even the advent of HIV didn't diminish the gayness of life, though after becoming infected with HIV I did find my loyalties divided between the gay and the HIV communities. Whether we like to admit it or not they were separate and if you were HIV+, it was hard not to hang out with others the same. They were our support group, our source of information and, in far too many circumstances, people to mourn with. Yet despite the camaraderie that came from within that community, I never really felt that I clicked into it. I loved my life being centred around gay, but didn't feel quite the same affinity with HIV. I tried joining groups and organisations but realised I didn't want HIV to be a central component of my life, something to hide behind when I didn't have an answer to 'why is this happening or why is that happening'. Even after a debilitating and life-threatening run-in with AIDS, I didn't want to get drawn too far into HIV's embrace. I went through all the steps involved to recover, then moved on. Yes, perhaps I do involve myself in that I write about HIV, but I always try to make it a background to what I do, never the forefront. I have pretty well also moved away from 'gay' and probably have as many straight friends these days, if not more. Life evolves.

Recently, we moved again (partner in tow). It's about two months since we moved and if we were ever to wonder just how well integrated we'd become within this new community, last Saturday answered our questions. It started with a chat over the back fence with our neighbours and a joint decision to work from both sides of the fence to repair our overgrown and neglected yard. We then got tied into a lengthy conversation with some other dog owners at the off-leash dog park. These people live in the next suburb and we get along very well with them, so a friendship will probably develop. The girls in the local café know us as Saturday regulars and make our coffees without us ordering. The owner of a local store drops in for his coffee and inquires how my recent purchases are going, followed by the manager and a staff member from our gym stopping for a chat about his recent holiday. I have to say that all this chatting and laughing made me feel very cosy and I realised just how much we were settling into our new community and had been accepted by those who'd been members for some time.

This really is what community is about: people getting along, interacting with each other and helping make everyone's lives that little bit more pleasant. I'm positive that everybody knows we are gay (it's pretty obvious) but no one gives a damn. They are not as nosy as my first community and I'd like it left that way. Tim

The communities I decided to engage with had to accept me for the person I was, not who they wanted me to be.
A few thoughts on 'gay community'

Where I live – Wollongong – there is not much of a gay community. I guess it is more underground here. (I consider this to be a redneck town, always have.) I know there is a gay community overall, but I don’t think it encompasses all gay people. It seems to be made up of differing groups and to me there seems not to be too much overlapping going on. (There are obvious exceptions, such as Fair Day and Mardi Gras.)

I don’t feel a part of any gay community these days. I did apply to re-join a local group I belonged to in the past but they never bothered to reply. My community is the complex where I live (over-55s only, singles mainly, men and women), my family and two golf groups, one of which knows everything about me and the other which knows nothing.

There doesn’t seem to be anywhere for older positive men like me to go, where we could just have a coffee and a basic socialising chat. Poz guys always used to stick together, but now the younger poz guys tend to treat older poz guys the same as neg people do – and that is to just ignore them, they will go away eventually. I know a lot of poz guys, old and young, go to saunas these days because there is a sense of socialising there. Even if nothing happens there is always a chat to be had, face to face.

I am wondering if it is just me or are there other men in my position who feel discarded? It’s apparent that older and positive in the gay community means one foot in the grave and the other on a banana skin. Even the online chat rooms are not interested. One particular one hardly ever acknowledges a contribution to the chat. There are a few who chat, but not for long – can’t be seen to be friendly with older poz guys, you know!

I don’t dwell on it, I have plenty to do most days ... well, some days. All in all, I don’t know if I want to be part of the gay community given the self-centred and shallow nature of a lot of gays. I’m happy being me. Tony

Community should not be used to define or constrict me.

I do feel a very powerful sense of community where I’m living, but community should not be used to define or constrict me. There is a tendency for outsiders to any community to make assumptions about how you, as a member of that community, behave and interact in your daily life. This tends to detract from the unique person you are. People sometimes do dress in a particular way to demonstrate a particular community or subcultural attachment. This is shown by Mardi Gras, where one night a year we put our community onto the street. While it presents our diversity, it also offers the broader society the opportunity to label us. So saying I belong to the gay community does not tell you anything about me as the individual and I think this is where ‘community’ can be used in a negative way.

For me to say I belong to a community makes me feel like I have a place. But while I have a sense of community, it will be a very different one to that of the retired couple who live next door, the horse whisperer who lives on the other side and the school teacher and her partner, a flight instructor for the air force, who live opposite. We hang over the fence and chat to each other about the goings-on in the street. Sometimes it does get a bit invasive, but it’s harmless for the most part. We all get together a couple of times a year. Our last party was a hit as we served up a banquet of Indonesian delicacies and I cooked up some of those CWA hit desserts of my mother’s, less some of the acrimonious flavour.

Telling people that I come from the country music capital makes them immediately think I’m into country music, which I don’t mind, but I also love Kylie, Madonna, Lady Ga Ga and Neil Young. So you can’t define an individual by their community, but it offers a reference point for further exploration – though I doubt you would get all this through using your iPhone apps! David

Bush or iPhone?

In contrast to the rural city where I live now, my sense of community was less definable when I lived in Sydney. Living in a big apartment block and not knowing the people who lived next door, in retrospect seems reclusive and insular. Now when I visit Sydney, I see the impact of social networking apps, which have taken over socialising and invade every moment, to the point of obsession sometimes. Sitting at dinner with people all around urgently fumbling for their phones when a notification goes off, while amusing, is also destroying the joy of social interaction. Having grown up on a farm where you only used the phone for the occasional business call, to organise a night at the pub or in an emergency, makes me wonder how healthy this new age is for us. Is community now defined within the confines of our palms?

I’m now far more gregarious within my rural community in comparison to Sydney. I fully expected to meet some sort of negative response to being an out-though-not-in-your-face gay male, open about being HIV positive and very different to the person who left the bush 27 years ago. My partner is Indonesian and Muslim, adding another dimension to our living in a rural city that we might have found challenging. I didn’t quite move back to where I grew up, but in country driving terms it’s close, at two and a half hours. I reconnected with the straight friends I grew up with, who hosted my 50th birthday party. They laid out loads of hearty country cooking, cakes and cream-laced desserts and more importantly they were welcoming of my partner and I back to the place I called home.

I was working overseas in 2003 when I got the call informing me that my younger sister, living in the country, had been diagnosed with cancer. The prognosis was poor, which made a reality of our previous flirtations with a tree/sea change. Leaving a secure life and job in Sydney, we braved the unknowns of rural life.

One of the biggest disadvantages of life here is access to healthcare, but I make it work. Very high on the plus list is the sense of a very strong and supportive collective of people around me I call ‘my community’. Expectations of what my community can provide for me have changed quite dramatically from when I lived in Sydney. Most of our friends here are straight, which I find a refreshing change from my previous notion that most of my friends would be gay-community-attached. Having grown up in a rural environment meant I’d had no overt role models and my perception was the stigmatising view that homos were artistic, limp-wristed fairies, poofs, dirty old men and uncles who lived very lonely lives and, most fearfully, could be arrested and locked up or treated with electroshock therapy. But on my return to the bush I have found nothing but inclusion. They have accepted my partner and I, rallying around us when my sister and then my mother were dying, totally on board when I was unwell. Knowing that I was HIV positive made no difference (though the temporary bipolar episode made things a bit shaky at times).
Community? Well, maybe…

I t was during a conversation over a cup of tea and chocolate mint biscuit that I suggested ‘community’ to the Talkabout editor. At the time, I momentarily wondered if my suggestion had been wise. After all, it’s not entirely unreasonable that there will be an expectation that the suggestion is backed-up by words on paper. So here I am, paying my dues for opening my mouth.

Why I suggested the subject of ‘community’ I’m not entirely sure. It’s not as though I’ve had an overwhelming attachment to the concept. In fact I find community rather a strange and foreign idea. My battered and well-thumbed edition of the Little Macquarie Dictionary describes it as ‘a social group living in a specific locality and having a common culture’. Mmm, this is going to be harder than I thought!

I’ve heard it said that if you’re asked to write about something difficult, write about what you know. So, I will write about where I live, my grandmother’s place, where I visited as a child, grew up, lived during a brief experiment with university and came back to 23 years later to settle down into middle-age and invisibility.

During my childhood, we would visit my grandmother at weekends and I was free to play with the local kids. There were five children next door – the eldest girl and next two boys were about my age. The four of us spent many happy hours together playing in my grandfather’s old car, exploring the abandoned quarry and cliff face across the road, the river and each other’s houses and yards. Two brothers, the younger about my age, lived in a house at the back of our property. He still lives there with his wife and youngest daughter. We have been friends for nearly 60 years.

In 1983 my grandmother suddenly died. This was the time of my HIV diagnosis and the gradual decline in health and death of my previous lover. AIDS was amongst us. More lovers and friends died in the coming years and the fear was palpable. An increasing struggle to maintain my physical and emotional health resulted in a decision to move from Surry Hills back into the old house. To go back to my roots, to familiar surrounds and memories, to a garden, to security in a sea of insecurity, to perhaps die in the bed of my youth, all factored into the decision.

The early 1990s were horror years. The house and garden became a haven for a number of our friends. Some moved in and subsequently grew sick and died. During this period, the garden proved to be a source of therapy and distraction. The parents of the kids with whom I had grown up were still living around me. Most were in their 70s or 80s and they were glad to have me back in the neighbourhood. We swapped plants and stories and they were a source of support. They also welcomed my house mates and their pets and seemed accepting of the garden parties and late night ‘comings and goings’. As the decade progressed, one by one, these old neighbours either died, or moved away. To my amazement, I was to become the last one left.

That house and those who have lived in it, or around it, or been associated with it over the years, will always remain in my memory – ‘a group of people living in a specific locality’, not necessarily ‘having a common culture’, but whose lives have impacted and influenced one another by association. Is that a community? I’m not sure. But I would rather it be a part of my life, than not. Laurence

The full story of Laurence’s family home will be a longer article in the next issue of Talkabout.
Once a week I do a volunteer massage for HIV+ patients. As a trained massage therapist with over five years of experience, I'm constantly asked the same question by my clients, who are almost invariably middle-aged men: "Are you one of us?" By which they actually mean, "Are you HIV positive too?"

There is always a real sense of relief in their voices when I reassure them that, yes, I understand the nuances of niggling neuropathy, constant painful twinges and strange, doctor-confounding ills that can befall a person who is a long-term sufferer. You see, I'm a massage therapist who has also been HIV+ now for eight years.

I actually began my training about six years ago at a course offered by an instructor who wisely believed it a good idea to give newly-HIV+ men an insight into their bodies, what makes them tick and what makes them tick better. Massage therapy is a skill for life, as well as a skill that can help and heal, for both the giver and the receiver.

My massage training took about six months to complete. It included two hours per week of intensive anatomy lessons, with a book to practice with, not a body, in case you're wondering. I had to learn multisyllabic phrases and convoluted names for parts of the body that normally only specialist doctors would know off my heart. In my course, of the 10 HIV+ men who began the training, only six finished. One disappeared never to be seen again, one became a crystal addict, another decided it was all too hard and another took his first three months of training and turned it into a business, touting himself as the 'massage therapist who gives happy endings'.

I finished my training with a 96 percent score, something I was very proud of, although I wasn't top of my class – a hunky Canadian-born guy scored 99 percent (though I did better than him in the practical assessment!)

Over the course of our training, our group constantly practised on each other, but the biggest challenge we faced wasn't concentrating on what we were doing or making sure we were doing it properly. It actually came when we had to massage a group of HIV+ women.

None of us was familiar with women's bodies and it was a truly eye-opening moment. As gay men we are generally so unfamiliar with the curves and nature of a woman that it took some major readjustment for us as massage therapists to accommodate them. It was a good lesson in what was to come as a masseur – everybody is different and some bodies are more different than others.

Although our course had been offered free, the deal we all agreed to was that on successfully completing the course and qualifying, we would have to allocate 60 hours of free massages to community services. Somehow for me that 60 hours has now become six years of offering my services to the HIV+ community.

Troubled bodies and minds

Most of the men I massage are relatively advanced in their HIV+ prognosis. Some have lived with it for over 20 years. One man told me he knows he has been positive since 1980, if not before. He witnessed his entire circle of friends, lovers and ex-lovers die before his very eyes in those early first years of AIDS. He is now somewhat bitter, quietly angry and rather fed up with life. The
massage I give him every few weeks helps alleviate the pain not only in his riddled body, but his troubled mind.

The one question I always like to ask my clients is what their job is. Some are still working and on my bench, laid out in front of me, I’ve had professions as varied as shopkeeper, actor/model, ad agency boss, librarian, historian, labourer, insurance man, personal trainer, healthcare worker, recovering addict and full-time nudist. Some of the men have been on sickness benefits for so long they can’t even contemplate the idea that they could once again be valuable members of the workforce. They never thought they would live this long, let alone be healthy enough to return to the jobs they assumed they were leaving to go and die. The meds changed things and kept them alive. Some of my clients are happy about this, yet others feel somehow guilty they survived. Some like to talk about how they feel, with the massage helping to ease their suffering and their inhibitions, while others prefer to just simply enjoy the serenity of being able to have their body caressed and touched like they haven’t been touched in a long time.

It’s a powerful reminder to me as to how important the sense of touch is. Although we often think seeing is believing, through my work with clients on the massage bench I have come to see that the greatest gift I can give to those who are suffering, or who have suffered hard, is simply that of a compassionate, caring touch.

No words

Sometimes there are almost no words before, during or after our one-hour sessions. Some people choose to lose themselves for the 60 minutes, regaining a connection with their body tissue that years of toxic medication, intensive doctor prodding and a raft of severe illnesses have left tenuous and tense. If I can help ease that tension, then I feel my work has been a success.

Generally my clients leave after the massage feeling the best they’ve felt in a long time. “I feel like I’m floating” is a piece of feedback I receive constantly. That’s when I know that not only have I done a good job, but I made the right choice in volunteering my services, rather than charging a fee and making it my full-time profession.

It’s a shame there are not more people from the HIV+ community who get involved in complementary therapies. Not only does it help you give something back, but also gives you a link to the past of the AIDS epidemic. It’s a way to help ease those survivors through the new era of manageable chronic illness.

More alive

One week recently I massaged a blind man who brought in his guide dog, which sat quietly as his owner groaned his way through our session. It was as if my client had not felt a human hand near his weakened body in a long time. He shook my hand firmly afterwards and I could tell he felt more alive.

I truly get a strong sense of satisfaction when I finish my volunteer session each week. Not only because I know I’m doing something good for others, but because I’m actually doing something good for myself. You should try it some time – you might find it as soul-enriching as I do. Greg Page
Got a question about HIV? If you or someone you know is HIV positive and you’re looking for information or support, visit us on Fair Day

One hour talking about Talkabout in Newtown

We’re throwing another readers meeting – so you’re invited! Meet the editor and discuss the magazine – what you like and what could be better.

Bring your ideas for the future!

WHERE: Come and talk over light refreshments on your way home from work or on your way out for Thursday evening: October 6th, 6-7pm.

WHERE: NAPWA offices
Suite G5, 1 Erskineville Road, Newtown (a minute from King St and Newtown station)

RSVP
Susan on 9361 6011 or editor@positivelife.org.au

CoastOut
Coffs Harbour Fair Day

WHERE: Park Beach Reserve, Coffs Harbour

WHEN: Sunday October 30, 11am to 5.30pm

Got a question about HIV? If you or someone you know is HIV positive and you’re looking for information or support, visit us on Fair Day

PositiveLifeNSW
the voice of people with HIV since 1988

www.positivelife.org.au
On a recent holiday to New York, Leo Reid was lucky to catch the Broadway revival of one of the earliest pieces of AIDS theatre, *The Normal Heart* (soon to be made into a film by the co-creator of *Glee*, Ryan Murphy). Later Leo spoke to Wayne Harrison, who directed the Sydney production of the incendiary play in 1989.

On a recent holiday to New York, I was crushed to learn that the revival of provocative activist Larry Kramer’s seminal 1985 play *The Normal Heart* was sold out. But as I was waiting outside the John Golden theatre on Broadway an hour before showtime one evening, hoping a ticket would become available, a stranger walked up to me and asked, "Do you wanna see the play? I've got a ticket but can't make it". As I was about to get some cash out of my wallet to pay the man, he rushed off into the night, telling me to enjoy the show.

But enjoy the show I didn’t. Instead, this play, which details Kramer’s raging activism as AIDS began to ravage his community in the early ’80s, left me feeling incredibly heartbroken for the millions of lives lost to this hideous virus. And of those millions, many were rejected, ostracised and discriminated against just because they were gay.

It made me angry that for way too long government bodies simply ignored gay men who were attempting to make sense of a virus that was decimating their friends, brothers and lovers. AIDS was ugly, terrifying and cruel. And it was happening to the men who had fought so hard for the increased freedom that we now enjoy and often take for granted.

At the end of the performance, as the names of AIDS’s earliest casualties were projected onto the stark white stage, the entire audience was in tears. It was one of the most gripping, powerful pieces of theatre I have witnessed in my life.

**Sobbing**

When *The Normal Heart* was staged in Sydney in 1989, the audience reaction was remarkably identical, suggests director Wayne Harrison. He says, ‘For the first time I saw how the theatre could affect, maybe change, people’s lives. I remember standing at the back of the Wharf Theatre during performances, listening to people sobbing. It was a highly emotional experience watching a man die on stage – you don’t actually see death enacted.’
very often in the theatre, but Larry Kramer didn’t want it to happen politely in the wings. His sense of urgency, his rage, wouldn’t permit it. I remember there being standing ovations – and some people too distressed to stand or even leave their seats after the final bows. They had to be helped by the ushers.“

When the play opened again in Manhattan this year, legendary critic Michael Musto urged his readers to “run to the Golden Theatre if you want to be reminded of how alive you are”. Musto was absolutely right. The Normal Heart was a sharp reminder to me, at least, of how relatively easy I have it compared to the men infected with HIV only two decades before.

**Twist of fate**

I’m 37, I’ve been positive since 2006, and while I was definitely aware of the stigma attached to HIV and AIDS in the 1980s, I had no idea of the crushing effect it had on our community. My only memory of AIDS in the 1980s was of course the infamous 1984 Grim Reaper ad, which frightened the entire nation. I was only 11 years old and wasn’t even aware of what sexuality or its consequences really meant for me. All of my friends discussed this genuinely scary ad campaign at school, but we were just as ignorant of AIDS as our parents, our educators and the government.

As I grew up in the 1980s, I had no real idea of the destruction AIDS was unleashing on so many communities around the world. I had no idea that like the characters in The Normal Heart, gay men at that time were literally fighting for their lives. Faced with equal measures of rejection and an early, ugly death, they were also insanely terrified.

It was only in the late 1970s that gay men were finally able to celebrate some sexual freedom after years of dedicated political activism. And then, by some cruel twist of fate, AIDS came along.

**War zone**

Wayne Harrison says that in Sydney, like most capital cities, “it was like being in a war zone. I remember one local journalist wrote a nasty column in the mainstream press suggesting gay men deserved this disease and the hideous – and what seemed then – inevitable deaths, so there was a real sense we were fighting not just a disease but something societal as well. And The Normal Heart wasn’t a fringe project, it was happening within a state theatre company. For some actors it was a big step playing gay characters in such a high-profile arena. This was true for the straight actors as well as the gay. So there was a lot of emotion in the room during rehearsals. Sometimes an actor would just flee the room in tears, so raw and, I guess, personal did he or she find the experience, the meshing of life and art. Sometimes actors were excused so they could attend funerals. But I remember the process being fluid, rewarding, fuelled by the thrill of doing something that felt right, artistically and politically. We were all compelled to act, by the power of Larry’s play and the urgency of the crisis in our own lives.”

So much has happened since then. Rapid leaps in scientific discoveries, the introduction of usually very effective anti-retroviral treatments and specialised care in the Western world has made the transition for the newly-infected these days a relatively easy one.

While I have often thanked the universe I wasn’t infected at an earlier age, seeing The Normal Heart made me feel incredibly grateful for all the men and women before me who suffered indignities, ignorance and injustices during their struggles. I am also grateful for the kindness of the New York stranger who offered me his ticket. Seeing the play has provided me with a new sense of awareness about our previous generation’s suffering and hard work.

**Kramer’s rage**

Larry Kramer is one of the most outspoken, unconventional and often-criticised activists of our time and he personally handed out flyers at the end of each New York performance this year, urging viewers of the play to acknowledge some home truths. I have no idea if Kramer handed me the pamphlet I was given because I was too devastated after witnessing the play to even look the person giving it to me in the eyes. However, the pamphlet is filled with Kramer’s trademark rage. In it, he states:

“Please know that everything in The Normal Heart happened. These were and are real people who lived and spoke and died and are presented here as best I could. Please know that AIDS is a worldwide plague. Please know that no country in the world ... has ever called it a plague or acknowledged it as a plague or dealt with it as a plague.

Please know that there is no one in charge of this plague. This is a war for which there is no general and for which there has never been a general. How can you win a war with no one in charge?

Please know that the world has suffered at the very least some 75 million infections and 35 million deaths. When the action of the play that you have just seen begins, there were 41.

I have never seen such wrongs as this plague, in all its guises, represents and continues to say about us all.”

**No sex, safe sex, unsafe sex?**

The play’s pivotal character, Ned Weeks, urges gay men to abstain from engaging in sex until the “plague” is either controlled or cured and Wayne Harrison remembers that back in 1989, “as co-owner of The Bookshop in Darlinghurst, I recall that people bought more books – either hungry for information or keen on a leisure activity that didn’t involve sex. We knew several gay men who stopped having sex with other men. One
Ryan Murphy has signed on to direct a Hollywood version of The Normal Heart.

Wayne Harrison thinks Murphy "will do a splendid job. For years Barbra Streisand had the film rights and kept threatening to make the movie. To Larry's chagrin, she never got it over the line."

Harrison says that "it's hard to speculate, though, what kind of effect it will have on younger audiences, not knowing [yet] what sort of movie Murphy or Hollywood will make. The potency of the play was that it was of the moment. It was recognisably our problem, our dilemma, our tragedy. Looking at it on film as a piece of American history might make it more about the power of the political activist – American individualism – rather than the ongoing threat of an incurable but manageable disease."

Our turn
Regardless of the future film's effectiveness, Kramer is now not only incredibly vocal about the fact that while we still need to fight HIV and AIDS, we also have another fight on our hands.

In this revised 2011 version of his show, the gay men of New York are urged to demand their right to marry each other. The day after I witnessed a performance, the historic bill was passed which allowed gays in New York the right to officially have their love recognised. The streets erupted with people jumping, screaming, hugging and celebrating.

It's now our turn in Australia. It's easy to get fatigued, repelled or complacent about activism. I'm guilty of it myself. But the hard fact is, until we are regarded as equals by our government, we have to keep fighting. It's that simple.

We also need to take inspiration from the HIV-positive men and women who, a generation before us, fought long and hard to be heard, to be treated as valuable citizens and to be provided with excellent health care. While some would argue that the stigma around HIV-positive individuals is gradually decreasing and life expectancy increasing, there is still a lot of work, education and prevention to be done.

And as the play will always potently demonstrate, no one else is going to fight our fights for us. Leo Reid
The National Network of Women Living with HIV – known as Femfatales to her friends – is a working group of the National Association of People Living with HIV/AIDS (NAPWA). The FemFatales network is a diverse range of women who advocate to improve the lives of positive women in Australia. The network also provides NAPWA with a forum for the discussion of issues specific and important to HIV-positive women and is an integral component of NAPWA’s women’s policy and advocacy.

Membership of the network is via expression of interest and is limited to 15 places. Currently there are around 12 active positions, so there is room for more. Women generally remain active members for about two years, depending on their circumstances. We aim to achieve equitable representation from all Australian states and territories and from women of diverse cultural and social backgrounds. The network also offers confidential e-mail support and strives to include all HIV-positive women in ways that best suit the individual and the needs of the network.

Femfatales currently works in the following key areas:

- **Sexual and reproductive health and wellbeing:** including advocating for equity for women and greater awareness of and access to female condoms – FC2 (Femidom). The network has developed comprehensive views on routine comprehensive antenatal screening and takes a keen interest in all matters pertaining to the sexual and reproductive health and wellbeing of HIV-positive women.
- **Capacity building:** Our members possess a range of skills and are developing methods to enable their productive use, both in advancing the aims of the network and to assist and support each other.

- **Stigma and discrimination:** The network recognises that stigma and discrimination remain strong impediments to daily life for some people with HIV and that women have unique experiences of this. We aim to raise awareness of these issues and advocate for equality, human rights and dignity for all. Members of the network are also engaged with the NAPWA research unit, which is currently undertaking HIV and stigma research in Australia.
- **Disclosure protocols:** The network is developing a set of protocols aimed at guiding HIV-positive women in regard to disclosure and confidentiality when dealing with the media, the public, service providers and other organisations.
- **Peer support:** Peer support has long been recognised as the most effective support for women living with HIV. The network membership is committed to strengthening and developing opportunities and approaches that promote peer-based initiatives – we meet via teleconference regularly, have ongoing email support and an annual face-to-face. (However, it’s important to realise that Femfatales is primarily a national policy and advocacy network.)

A further aim of the network is to foster meaningful and productive collaborations with likeminded organisations and committed individuals. If you’re interested in joining or wish to chat with a member of the Femfatales, please feel free to contact us via NAPWA. Your enquiry will be handled with the utmost respect and confidentiality. **Katherine Leane**

**Further information:**
- NAPWA: freecall 1800 259 666

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**Women's PozQuest workshop**

For women facing the challenges of HIV, with Petrea King’s Quest for Life Foundation

**Dates:** Monday to Friday, November 14-18, 2011

**Venue:** Bundanoon, south of Sydney

**Cost:** $120 per participant

For further information, contact Peter Thoms at BGF:
(02) 9283 8666; freecall: 1800 651 011; email: peter.thoms@bgf.org.au
At age 50, **Stephen Berry** collapsed with an AIDS-defining brain condition. Now approaching 60, he has recovered enough, against massive odds, to go rafting, scuba-diving and bungy jumping.

Massive intake of HIV medications became the order of the day and night. Everyone was worried big time. My partner of seven years, my family, my colleagues, my doctor and neurologist were equally concerned.

The medications shot the HIV viral load to ‘undetectable’ within just six weeks. My neurologist advised me he would stop me dying but that recovery of lost faculties from PML was extremely rare.

**Death threat**

I was exposed to HIV on a trip to San Francisco in October 1983, only 18 months after coming out in my late twenties. Diagnosis as positive was in June 1985 and my then-boyfriend would be dead within three years. So having watched friends and ex-partners pass away over the past two decades, my best prospect now was life as a disabled pensioner – if I survived.

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Fifty was not a good year for me. After 20 years with HIV using only natural therapies, I experienced a major immune collapse. The virus had finally got the upper hand. The same week that I graduated with an Advanced Diploma of Applied Aboriginal Studies from Tranby Aboriginal College, a brain MRI confirmed the worst. PML (progressive multifocal leuko-encephalopathy) was a major AIDS condition short-circuiting the myelin nerve sheath of my cerebellum. The odds of death were 50/50 within six months to two years. Viral load shot up to over 80,000 and T-cells disappeared – only 85 were left, along with very few platelets and thus bruises all over my body.

I should have started HIV medications at least a year sooner. PML had delaminated the nerve sheath of my brain and the damage would spread. Within three months I had lost bladder control, balance, the ability to write and drive. The loss of speech started to challenge my use of the phone. Soon I became too weak to get up off the floor if I fell and had to head for the bathroom every two hours throughout the night to have a pee.
I was getting around on a walking frame and could not even sign my name. My brain was partly dead, but my psyche had not registered the death threat, even after seeing so many others depart. Four years prior to all this, my partner had done a year of chemo to deal with a KS diagnosis. After that experience, friends had questioned my wisdom in continuing to avoid HIV drugs. Now I felt dumb, dumb! Self-doubt and anger opened the floodgates of regret - 'you will now pay'. Every sense was numbed at the enormity of my situation.

Yes, I had done much in my 50 years. Yes, I had a wonderful partner, family and friends as extraordinary support. But things worsened. After the first couple of weeks on the strong medications, I was feeling so much sicker and weaker. A change of medications to include the original AZT got rid of the nausea but took me back to my teen-age, with zits all over my face, forehead and shoulders. Weeks later came an outbreak of shingles around the left eye socket – the high risk now was weeks of blinding pain and the loss of vision in that eye.

We pulled apart my bathroom, removed the slippery bath, installed a large shower big enough for a chair, and added grab handles around the apartment to give me a greater chance of stemming falls at home. The loss of vision did not ensue, but we had to check it every three months. I continued natural therapies like acupuncture, shiatsu and reiki. NorthAids at Milson’s Point [which has since closed down] provided an expanded range of therapies, including Pilates and tai chi. I had a two-week respite down at their Dee Why Lodge to give my partner a much needed break.

**Turning the tide**

At 51, the immune tide began to turn in my favour. My neurologist gave me a restricted permit – up to 10 kilometres – to drive again. On one of these excursions to NorthAids in my little Citroen 2CV, a new friend came into my life. Parking outside a Milson’s Point café was the catalyst for an introduction to a car enthusiast having brunch there. We started as fellow enthusiasts, but Robert’s interest soon swung to my physical constraints and the story of my journey from HIV to AIDS and PML. I had no balance, trouble stabilising a cup of cappuccino, writing was totally impossible, I could not run. But Robert thought he might be able to help with a super-probiotic yoghurt he had spent years developing. Maximising my body’s potential for healing resonated with me. Robert supplied the yoghurt without cost for over a year. Developed from a human culture, it came in dried sachet form and had to be mixed with UHT full-cream milk and incubated for 14 hours.

Within days my sloppy, smelly poos became odourless, perfectly formed, floating in the toilet bowl! Within a week of Progurt I no longer needed the homeopathic drops necessary to rehydrate my skin, parched by both HIV and the medications. Mornings heralded a new era of healing. For over a year erections had been relegated to a bygone era. Miraculously, I awoke one morning with a strange reminder of a more youthful past! Brilliant, stunning. Now I knew I was not going to die. Now I was sure healing would be my journey.

After five years of this turbo-charging my digestive system, blood tests have shown something curious. Virtually all my organ functions, including the liver, are within normal range, which is amazing considering the number of HIV meds I’ve taken to quell the virus to undetectable. I’m convinced that optimising the digestive system has helped me to a renewed quality of life.

**Not dead yet!**

Reflections of what life might now become set my mind probing what it meant to be 'Stephen'. From very scared and very lost, new stages of excitement enlivened the disturbed grey matter. Acronyms emerged expressing the new possibilities. PML became Potential Miracle Land, HIV became HealingInner Values and AIDS became Assists Individuals to Develop Spiritually!

A good friend offered the air fares for a trip to the South Island of New Zealand for my partner and me to celebrate: *A Not Dead Yet Recovery Tour!* One year after the PML diagnosis, we were overnighting on Doubtful Sound, visiting dolphins, seals and penguin colonies after a week of brilliant blue skies, mountains, lakes, glaciers, caves and snow. On our return another colleague bought me a laptop so I could learn to type again to partly replace my lost ability to write.

It should have been a great Christmas. But, having nursed me back from very poor prospects, my partner announced he was leaving me for someone else. Someone he had loved before we met was now single. Anger replaced the sense of hope. For six weeks after he left I was very shitty. Then a new perspective dawned: I loved him, I did not hate him.

I invited him to lunch in the park near where he worked. Fish and chips shared beside the flowerbeds celebrating new growth. A shared smile invited me to open my heart. "I love you so much, I just want to see you happy. It is not about you making me happy. It is about you finding your own happiness."

**Happy returns**

For a couple of years we hardly saw each other. The lost faculties accelerated in their return. The hard-ons became a joystick for my sole attention. I returned to part-time property work. And another return happened. We started to date again. Soon it became like two schoolkids with a first love blossoming. Everything was magical, romantic. The love grew and grew.

Age 56 saw a myriad of celebrations for my birthday week in Cairns, where I met up with a HIV+ doctor friend from the US. A bucket list ensued. Together we set off white-water rafting on the Tully, hot air ballooning over Atherton Tableland, microlight flying over the Inner Reef, scuba-diving and snorkelling, strolling in the rainforest, swimming under a waterfall, plus forward and reverse bungy jumping. A few months later this was capped off with the Australian Property Institute Award of Excellence in Valuation for the *PML Ghost that Walks*!

My doctor calls my recovery a miracle. My neurologist calls it amazing. A visiting London neurologist wanted to see the one who had defied medical expectations with PML.

At 58, I feel deeply blessed. There is a huge shared love with my partner. All around I have been hugely lucky. The return of love, the return of health and the return of healing after nearly 28 years with HIV and eight years since PML. Maybe I will even learn to run again by the age of 60? *Stephen Berry*
When I was three, so I’m told, I would often sit with Lego blocks or paper and pencils at the coffee table, chin in hand, elbow on table, in the classic pose of deep thought. Mum would smile and walk away. Ten minutes later she’d return and I wouldn’t have moved.

"Peter, what are you doing?" she’d ask. "Thinking," I’d reply. Mum would ponder what a child of three had to think about.

Another 10 minutes and another 10 would pass. Suddenly, the building or the drawing would begin and then continue for hours. A glass of milk and homemade cookies would be supplied as I busily worked. I was so happy to be lost in my creative world, time stopped, peace reigned. When done, I’d sit back critically, viewing my work. Mum has said that unlike most kids, you didn’t need to ask, "And what have you drawn or made there?" because it wasn’t an unrecognisable scribble or amorphous lump of Lego. Mum would simply say, "Oh, what a nice cat" (or "robot" or "castle" or whatever it was that I’d created).

As my life had begun, so it has continued, though not with cats, robots or castles.

**It gets better**

Throughout my school years, art and creativity in any form was my joy and my escape from the cares of the world. However, it was the 1970s and ‘the arts’ were considered an abnormal interest for a boy. At my school, only one such subject was allowed. So I chose Art. English, Science, Maths and technical drawing were also among my subjects, which was fine as my hero was not a footballer or cricketer but Leonardo da Vinci and these subjects were his as well. Perhaps needless to say, my scholastic loves were the cause of my hellish school social life of taunts, abuse (both physical and mental), eroded self-esteem, shyness, fear and loneliness. Art and study were my refuge and comfort. I loathed being at school and the people in it. However, as the recent global campaign against gay teenage suicide states, it gets better.

Eighteen and freedom from high school and independent living arrived. I enrolled in a BA at the

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For Peter Schlosser, the creative energy that surfaces through his art is a true life force.

*J Fools & The Wise Ignored, 2001, oil on canvas.*
lymphoma. I was given a prognosis of two weeks to live and only a five percent chance of surviving the toxicity of chemotherapy. I slipped into a coma. It was the best bloody thing that's ever happened to me. Exactly a week later I came out of the coma, unafraid of death, no longer shy, joyful at another chance at life and all the experiences it brings that I so much wanted. Ill as I was, I had an inner conviction that all would be well. I demanded that art supplies be brought into hospital so that I could create.

**Full spiral**

Despite the negative expectations, I survived nine months of chemotherapy. The final result of this was remission from cancer but with a shattered immune system. I had a T-cell count of 28. I could not go out in public. Visitors were kept to a hygienic minimum. One year later, without further treatment, my T-cell count was 550. Everyone except me was surprised. I decided there were a lot of things I wanted to do. One of them, following the care and love of friends, health workers and total strangers during my illness, was to give back to people in some way. I only had my art, which was a joy to me, and I hoped to share that joy. So I enrolled in a Dip Ed course and became a secondary school teacher in Fine Art and Design.

Before I'd finished the course, I was offered a job by the Department of Education at a school one suburb away from the one I attended as a teenager. The irony of becoming a teacher in the area I grew up in did not escape me. You could say I'd come full circle. I prefer to say I'd come full spiral, in the same place but as a different person, with a different attitude and a newfound confidence and passion.

University of Sydney, a double major in Fine Art and English Literature. It was a time of growth and discovery, a time to accept my sexuality with a sense of happiness. Then in 1984 at the age of 21 and happily in a relationship, the grim reaper took it all away. I had HIV and was told I'd not see 25. Hopelessness took over. People started dying and were even committing suicide upon diagnosis. I continued to work but I'd lost meaning and purpose. I was privately waiting to die. I even gave up on my art for two years. Then I went back to college in an attempt to cheer myself up, doing a BA (Visual Arts), majoring in Design, with no thought of career paths.

The turning point was reaching 25 fit and healthy and discovering that statistically I would probably not die till I was 32. I'd finished the degree I loved and in which I'd made lifelong friends. Little did I know, I was already ill and was insidiously and progressively approaching the threat of death. In short, in late 1990, after two years of doctor consultations over a set of bizarre and seemingly unrelated symptoms, I collapsed at a family dinner. Three days later, frightened and delirious, I was admitted to the St Vincent's AIDS ward with stage four Hodgkin's
Teaching Art and Design was the first job I truly loved, though it was to be a bittersweet experience. My partner of eight years had just had his first AIDS-defining illness and began to waste away. I felt guilty at being so happy at work while my partner was slowly dying.

I found that the gratification I got from seeing students’ confidence grow, watching them achieve beyond their own expectations and develop a love of art, was immense. With that came a burgeoning desire to produce my own artwork. Teaching left no time for this though. In my second year as a teacher, as I cared for a dying partner, I relapsed with cancer. Chemo began immediately, as did the damage it causes. I was determined that my students would not lose their teacher until they’d progressed to their exams. Teaching and art were the only things that helped me cope with my partner’s and my own illnesses, both as therapy and as escape.

**Life without vision**

In October 1994, my students were ready for their exams. I was frail and ill and took leave without pay to have my final cycle of chemo and care for my partner fulltime. Art, creativity and joy were set aside. Both of us were in and out of hospital, but never at the same time. We were always crossing paths. My partner died at home post-Christmas 1994. In January 1995, just before my 32nd birthday, I was rushed to hospital with a temperature of 42 degrees with a MAC infection. In the following two weeks I was diagnosed with KS, cholecystitis and last of all a toxoplasmosis infection on the sight centre of the brain, causing blindness and an agonising headache. My partner of 10 years and my beloved job were gone and I was facing eviction. Teaching left no time for this though. In my second year as a teacher, as I cared for a dying partner, I relapsed with cancer. Chemo began immediately, as did the damage it causes. I was determined that my students would not lose their teacher until they’d progressed to their exams. Teaching and art were the only things that helped me cope with my partner’s and my own illnesses, both as therapy and as escape.

**Recovery and damage**

Recovery was long and slow. I was told I’d be dead by the end of 1997 of either cancer or AIDS. In 1996, with my superannuation and death and disability payouts, I was in New York visiting the Guggenheim and Museum of Modern Art galleries.

When I returned to Australia I began to draw, paint and sculpt. At 1997’s end, my T-cell count was in the 500s, my viral load was undetectable. If I could remain in cancer remission, I’d live a good while longer. In 1999, I celebrated five years of remission and with a dear friend’s help set up a fine art and design company. Lately I’ve been doing more interior design work than art work. The process and the feeling I get from this is very much the same for me as creating art. It lacks one thing, though, and that is that it’s not quite as personal or meaningful for me.

**Same place, different person**

My passion for the creative is unending. It allows me to go out and observe, contemplate and question the world, its beauty and ugliness. In the process I understand others and myself better. I then go home or to my studio, which is my late Dad’s workshop at the back of my childhood family home. There I enter that glorious world where time, daily concerns, illness and even pain vanish into oblivion. Thinking, dreaming and creating, as I did aged three. Again this is a case of full spiral – same place, different person. Most of all I’m happy and content, barely containing the anticipation of sharing my work with others. Art gives me purpose, challenge, pleasure, reward and joy. Sometimes it even gives me goose bumps.

Missing teaching, I joined the Positive Speakers Bureau in 1997. I use my artwork to challenge people, to get them thinking and hopefully impact positively on their lives. Speaking is another avenue that achieves these goals. Recently I reconnected with my former university and other designers and artists. I have plans for artworks in a variety of media for several different exhibitions, some of which I’ve begun. In the event that I can no longer produce art, I will have the time to use my computer to write as I’ve always wanted to and have often been asked to do. As I view it, writing is art too. Art is a necessity of life for me, like food. A life without art? I don’t think so! Peter Schlosser
NEWLY DIAGNOSED HIV+ WANT TO TALK?

Nexus is a peer support / discussion group developed exclusively for newly diagnosed HIV+ gay men.
> Compassion and understanding
> A place of safety
> A willingness to listen
> Accepting and non-judgemental

Next meetings:
Monday, September 26
Monday, October 24

For more information email hivliving@acon.org.au or call 9206 2101/2102 and we’ll get back to you asap.

KARUMAH POSITIVE LIVE-IN WORKSHOP

WHERE Tiona Sundowner Tourist Park, Pacific Palms (near Forster)
WHEN 18-20 November, 2011

A weekend away for people living with HIV and their carers

Activities include:

• Workshops
• Guest speakers
• Complimentary therapies
• Beautiful resort pool and 10-seater spa
• BBQ facilities
• Wide variety of walking trails
• Lake and beach

To book, contact Robert or Gillian on 4940 8393. All-inclusive cost $10.
Sonny Williams started work at Positive Life NSW in mid-July. Here, Susan Ardill explores our new CEO’s back story.

Susan: So, you’re Sonny!
Sonny: I certainly am – in other ways too, sunny by nature!

Originally from New Zealand, Sonny moved to Australia when he was 21.
Sonny: Just thought I’d pop over and see what was happening and have been working up and down the eastern seaboard of Australia ever since.

Susan: Had you already come out as gay?
Sonny: Yes. I came out at 21. My mother was a bit surprised, which is interesting, because my whole family and my aunts had had this conversation when I was growing up, ‘We think he’s gay!’ Yet the minute you used the word and made the statement that you were gay, they were, ‘Well, no. This can’t be happening!’ My mother went into shock for a couple of years, until some family friends said, ‘Get over it! You’ve always known. What’s your problem?’ And we moved forward from there.

Sonny has been HIV+ for over 12 years.
Sonny: [Finding out] was an absolute shock. But it happened. I literally made a decision, when I got the diagnosis, to either get over it and get on with life or I could sit back and wallow. I chose what I call the up path. I had a memory of meeting with an employment agency a couple of years prior to my diagnosis, where they said, ‘You can do anything you want to be. You’ve got the skills’. That’s been, I guess, one of my mantras. You can do whatever you want to, if you’ve got the mindset to do it and the energy.

Susan: Have you always been that optimistic?
Sonny: It’s the way I’ve been brought up. We’ve been brought up to give back to the community we live in. My parents still give back to their community and my father is 77 and my mother 75. It’s part of the whole family ethos. You get back what you give. It’s just a natural thing.

Within 72 hours of finding out he was HIV positive, Sonny had told his parents about his status, a testament to their closeness.

Sonny: [We are] extremely close, despite the fact that our politics are at different ends of the spectrum. My mother’s a very conservative woman, massively conservative.

Susan: Do you feel like an Australian or a New Zealander?
Sonny: I’ve spent most of my adult life in Australia. I came over when I was 21 and I’m now 54. When I go home, New Zealand has changed so much. I feel like a stranger in my home country, despite the fact that I have some very strong family ties and attachments there. So I just tell everyone I’m a citizen of the world, because I’ve also been able to travel extensively, so I have connections and extended family in Canada and the US. And I’m getting to know some friends in Bali. So I’m just going to sit with ‘citizen of the world’. Who knows where I’m going to land?

Sonny’s early working life was a mix of retail and a little bit of advertising and a smidgeon of clothing design.

Sonny: I suppose you could say my specialty is change management processes. That seems to be the most common thread through my entire working life … looking at systems in private enterprise organisations that were, perhaps, not doing as financially well as they could
and looking at ways to move them forward and improve, without making too many internal changes around personnel. In retail, it was clearly about the product, sexing the product up.

Susan: Had you been involved in any sort of HIV politics before your diagnosis?
Sonny: Nothing! My primary involvement was caring for my partner at the time or friends within our network. I've never really been involved in the gay community. I have a broad network of friends. That's not to say that I don't know what's happening in the gay community, I simply don't describe myself as embedded in the gay community. But then some other people would say, 'Well, yes you are'. It's a personal perspective.

Working at ACON from 1998 to 2005, firstly in community development, then as manager of western Sydney, was Sonny's first active involvement in the HIV sector.

Sonny: For me, working at ACON was one of the most rewarding experiences. I was there during a period of change and growth for the agency and I found it stimulating. I don't think I'd be where I am today if I didn't get that grounding. I'd moved down from Brisbane – my relationship had broken up, so I decided to move back to Sydney and just fell into the sector, really. I describe myself as the 'accidental tourist'. I'm still touring.

After ACON, Sonny went to Melbourne for six and a half years as Executive Officer for People Living with HIV/AIDS, Victoria.

Sonny: Once again, that was a stimulating six and a half years.
Susan: Cold?
Sonny: Cold! Yes, cold, but a beautiful city – quite an easy city to navigate around.
Susan: What's the difference, in a general sense, between Melbourne and Sydney?
Sonny: Pace! It's faster here, though I've seen significant growth and change in Victoria, where the pace has picked up as well. It's a style. It's the layout. Melbourne struck me as being very European. You can be in the middle of the city and not realise you're in the middle of the city. For instance, these magnificent sandstone buildings – the centre of the city is quite old, with wide avenues, tree-lined avenues. Just an interesting, almost Parisian feel, with the wide boulevards.

I'll miss some really good friends and colleagues from Melbourne, but each city has its compensations. We've got the harbour here, one of the most beautiful harbours in the country. This is my third working stint in Sydney, in the 30-odd years I've been in Australia. I have a very strong network of friends here and, clearly, having worked in the sector for 12 years, in different capacities, I am fairly well networked as well. It's like coming home, in a sense, but wherever I am, it's my home. I can see the benefits of being wherever I am.

PLWHA Victoria was a great learning experience for both the agency and myself and for the community. It was a very supportive community.

And there were a lot of changes, significant growth over the six and a half years. That occurred through a whole range of processes, with massive support from the Board, from staff, from community, service providers and, of course, the funder. There was also the issue of rising HIV infections in Victoria and being asked, as an agency, to step up – those are my words.

We moved down the health promotion path, using community development models, using strong evaluation processes and using those processes as a means to develop strong funding submissions – so evidence-based funding submissions.

I think that agency has done incredible work and continues to do incredible work with the sector and community.

[As an executive officer] I have an open door policy. I'm quite happy to be challenged to the last minute on processes and decisions, a collaborative approach, understanding that, at the end of the day, as the head of the agency, I'm absolutely accountable and answerable for any decisions that occur within the agency.

Sonny is also Vice President of NAPWA (National Association of People with HIV/AIDS), a role that grew out of his position in Victoria.

Sonny: NAPWA holds an SGM every year and as a peak agency, PLWHA Victoria has a seat at the SGM and we provide input, as do all other PLHIV agencies in the country, to the work NAPWA performs and to the high-end advocacy work NAPWA carries out in Canberra and within states. [My role in NAPWA] was an interest that grew from there. It sat alongside the growth that PLWHA Vic was going through. It was a way of transferring what I was learning and what was occurring at NAPWA and we could both learn from each other.

Susan: Historically, NSW was the epicentre of the epidemic and of the politics, in a sense. Has that changed?
Sonny: Each state has its own unique set of politics. I'm certainly finding this role in NSW operates at a higher policy level, whereas in Victoria, you moved between the different levels and the Board worked with you across different processes. But [in my role here] there's a much higher level of engagement with the different HIV agencies, which is an excellent learning curve.

Having come from Victoria, an agency which has experienced growth, within six and a half years, to NSW, where it's a larger positive community – there are similarities, but there are differences and it's, in a sense, mapping some of the experiences in Victoria and seeing how we can use them here and seeing how we can use and learn from here and map it down to Victoria, because we have a close working relationship with other PLHIV agencies. It's a sharing of information, experiences, policy, programs and staff.

Susan: What do you think are the big issues now facing people with HIV?
Sonny: HIV and ageing; health reforms being enacted, from both a Federal and state level, such as the PCEHR; remaining in the workforce/planning your retirement – what might that look like; other health factors (diabetes, etcetera); and the access to disability support processes, which will change next year. I'll be curious to see how some of these impact on our constituency and membership and how do we work forward.

Housing is an interesting conversation to enter into, given that we have a changing epidemic. The needs of people with HIV are changing and the model around housing is changing and I think we are going to have to do some work with the membership and the consumer around what those changes mean for access to affordable housing, because frankly, across the country, there is a huge public housing shortage. We have a duty of care to be more reflective about the housing stock and be real about, if you want to live in particular areas, what that's actually going to mean. It will mean, for some people, looking at compromises.

But we are also talking about HIV becoming or, in some areas, being talked about, as a manageable chronic disease. So, as that changes, I think, clearly, some social welfare benefits could be eroded/replaced over time with new systems, which will involve a new set of work. We're looking at people with HIV remaining in the workforce longer. The health issues are going to be slightly different – the effects of longterm medication, perhaps diabetes at a younger age, issues around cancer, liver problems, cholesterol problems and the question that's going on and the research that's happening around the internal ageing of people with HIV and what does that mean...

In many ways, Sonny is typical of the 'second wave' of people with HIV, who became positive after effective treatments had become available.

Susan: You've been on treatments for some time?

Sonny: From day one. Kind of a hit hard, hit early approach. I've always had a high CD4 count and undetectable viral loads.

Susan: So you basically haven't had any health problems and you're obviously in the workforce...

Sonny: In the workforce, more than 35 hours a week! And active socially, with my friendship networks, family and in travel. I have family commitments overseas and I often have to go home to do work with my family. So, yeah, I'm fairly typical of the new generation, for want of a better word, even though I am older in the chronological sense.

I think there is potentially a tension between the older generation and the new zero converters. It's just something that you have to work with and acknowledge … as long as you acknowledge it. The virus affects people in different ways.

Susan: What about younger people, people under 35, say? Some people speculate that that younger generation of people isn't necessarily going to be as community-minded in the same way as people who have been with Positive Life for a long time.

Sonny: I think the engagement is there, it's just at a different level. We're talking about IT-savvy young people whose social networks are completely different, whose identities can be fluid and so their interactions are conducted in that same way. But they're moving into the sector, picking and choosing what they want to do.

The visibility of HIV has changed and will probably change again. In 10 years time, we'll probably be having this conversation again, asking about the younger generation and their involvement, as agencies change, as we're asked to review, build our work and change focus. Not change our identity as to what our organisations do, but we are becoming more involved in prevention.

We talk about positive people being central to HIV program development – nothing about us, without us’. Then you map onto that the Ottawa Charter and human rights ... it makes for interesting work, very interesting!

I was having a conversation with a couple of colleagues yesterday who are slightly older than me. We talked about what we thought our retirements would look like and none of us thought we would retire early. We thought we'd be working past 65, not necessarily in the sector, but engaged in some form of work.

Treatments have made this kind of conversation possible.

Susan: That's a big change, because people with HIV certainly weren't talking about their retirements 20 years ago...

Sonny: It puts you in a privileged position. Working in the sector, you have to be mindful of that because I represent a broad body of people. One of the things that I try to be careful about is not mapping my experiences onto others, because my experiences are different. I think the challenges, for Positive Life NSW, are HIV and ageing, prevention and the new models of care and 'treatment as prevention'. Then there's the move, in some countries, to medicate as soon as you get a positive diagnosis.

Susan: I've read some very heated exchanges on the American internet about 'treatment as prevention'.

Sonny: It's very interesting. Once again, who pays? Sometimes you need to put a Federal lens on some of the issues. We are but one part of the community, who is vying for new medications and new, innovative ways of working with chronic illness. I'll get crucified for that one! (laughs)

Susan: But that, presumably, is increasingly going to be an issue, especially as people with HIV age, they become more and more seen as just part of an ageing population who have health problems.

Sonny: Absolutely! The difference is, you could be 40 and have something that may usually occur in your sixties. So the challenge, as a person living with HIV, is getting your head around it. But the other side of the coin is getting services to reorientate. Aged care is a perfect example.

It's not going to be dull, that's all I can say! I have met some amazing people in this sector, both people who provide services, but also members of the community, who just have incredible stories and who know how to advocate for what they're after. There are some strong people in the community, who are just getting on with their lives, but using some newfound skill sets. This work is never dull. There's never a day that isn't interesting or that you don't learn something. 😊
Phoenix weekend workshop
Tweed Valley
Friday to Sunday, October 21-23
Gunnebah Retreat Centre via Murwillumbah

For people with HIV (residents of northern NSW) who are considering a positive life change.

Includes: Accommodation with all meals provided, free time, a complimentary massage, meditation and yoga classes.

Venue: Gunnebah Retreat Centre, 586 Nobbys Creek Rd, Nobbys Creek, via Murwillumbah.

Cost: $60 per participant (to be paid by Oct 7, 2011). Participants need to be registered with BGF.

For further information: Kit Ayers at BGF on (02) 9283 8666 or freecall 1800 651 011

This Phoenix program is a joint venture between ACON, Bobby Goldsmith Foundation and Lismore/Tweed Sexual Health Service (SHAIDS).

MAKING IT WORK
Lismore, Saturday October 1, 2011

You, HIV and the health system – a one-day workshop.

Enrol now
Contact Lance on (02) 9361 6011 or Neil on 1800 633 637
Email: lancef@positivelife.org.au

PositiveLifeNSW
the voice of people with HIV since 1988
I was born and bred in Sydney, residing till the age of one at Milson’s Point just across the Harbour Bridge. [I never quite understood that term ‘born and bred’; it seems like a kooky anachronism.] Mum, Dad, my two brothers and I squeezed into a dark, red-brick Federation-style flat. Not that I have a visual memory of this time, but I do have photos.

Then our family moved from town, as it was called back then, to our groovy new pad (which Dad designed) in the lush and nature-filled environs of Bilgola Plateau on Sydney’s Northern Beaches. My parents were thrifty people with flair and vision and this didn’t miss the editor of *Australian House and Garden*, who featured us as a cover story in the June 1972 edition. In one grainy black and white photo I can be seen watching my brother astride one of those inflatable, bright orange, bunny-eared bouncers that were all the rage!

**A bush childhood**

I was a big fan of Skippy, was a fully paid-up member of the Gould League and had more reptile pets than toys. Our back balcony played host to a variety of colourful and chatty birds. I recall warily and respectfully dodging the female wedge-tailed eagle on the bush path to school. If she was nesting, we had to be extra cautious. Imagine the magpie-swooping trauma but four times the size, with razor-sharp talons capable of snatching a small child!

Afternoons and weekends were spent exploring pockets of rainforest, the mud flats of Pittwater or the beach. I remember winning a competition for my intricate pencil drawing of a huge tree for a local flora and fauna organisation and I beat the whole school at orienteering. I simply loved living there. It was essentially outer suburban bush and I think it left an indelible earthy print on my nascent little mind.

Not long after my eleventh birthday, I recall Mum and Dad showing us a huge map of Australia and telling me, my brothers and sis that we were moving to Perth so that Dad could use his engineering skills in the big WA mining boom of the 1970s. So, in the grand tradition of Alby Mangels and the Leyland Brothers, we ventured across the biggest island on Earth. Let’s just say it was a paradigm shift! I can proudly say that I’ve driven from Perth to Sydney and back at least three times and one time I was accidentally left in the Nullarbor Plain momentarily!

**Urban life**

I stayed in Perth until a year after high school, then came back to Sydney to be around more like-minded people and to discover myself after years of internalised and external isolation in the then not-so-wild west! It was a decade prior to my HIV diagnosis, but my sexuality was the hot topic back then and I needed to be in a nurturing environment to express it fully.

My life as a positive open book

Tobin Saunders joins the library – as one of the books.
Living Book

A local

About six months ago my manager suggested I become Self-publication

to settle back in Sydney, where I lived socially, culturally and topographically in the very heart of the beast. It all got too much for a number of reasons and having seen a bit of the north coast, I found my way towards the Byron Bay region quick smart. I’ll never forget one trip where we passed through Brunswick Heads and deep down I knew that one day I’d be living in the area.

Space, nature, peace

All up now I have been living in various parts of the stunning Northern Rivers region of NSW for 10 years. Several peers and a posse of cynical Sydney folk said I would never last and that I would go crazy or get cabin fever. I left the big smoke running – during a really successful career as a promoter and performer/activist – and I have never looked back. Sure, I still do my gigs around Australia and I certainly pop down to sin city from time to time for cultural and social delights, but I have no desire to move back there. Even if I win Lotto I won’t be enticed to live there, I’ll just have a chic inner-city crash pad!

It’s true: the transition from city to country can be tricky, but having always loved the tranquil bushy surrounds of my formative years, I didn’t feel like a duck out of water when faced with this fecund landscape. After a few local moves I’m now settled in semi-rural South Ballina and I love it! Plenty of space, lots of nature and hardly any people around to disturb the peace (if you don’t count the pesky skydiving planes buzzing overhead).

I’ve kept pretty much to myself over the years but I do spend time with a small group of close-knit friends. I guess all those years of being in the eye of the social storm took its toll and these days I’m disinclined to seek endless social networking. I still stay in touch with my Sydney friends and other mates around the country. It’s true that you need to keep a balance in life. This balance shifted dramatically when I successfully applied for a health promotion job at ACON Northern Rivers. Having semi-isolated myself, I’ve now been flung into the social and community miasma of the region and it’s been fantastic. I meet so many people and share so many stories, from local mayors to indigenous elders and everyone in between.

Self-publication

About six months ago my manager suggested I become a local Living Book. I’d been a Living Book a couple of times in Sydney during Mental Health Week and enjoyed it enormously. I adored the unexpected social frisson that it created. The Living Library originated in northern Europe and Lismore became the first Living Library in Australia. The Living Library works exactly as a regular library, only the ‘books’ for borrowing are living books – people. Borrowing a living book fosters an appreciation of the individuals who make up our community and allows us to reconsider stereotypes and prejudices.

The library has a large selection of ‘books’, from a Sudanese refugee and a vision-impaired author through to a person with schizo-affective disorder. The title of my ‘book’ is Gay HIV-Positive Performer/Activist and I’ve been read now about 15 times. Part of my induction required me to ‘read’ several of the available books as a way of listening to different stories and story-telling styles. So here I was, delving into the complex and amazing lives of Northern Rivers people. These experiences have reiterated and expanded my understanding that human nature and diversity exists wherever you are. It’s helped me realise how much we may simply judge a book by its cover and maybe walk the streets full of false (or at least misleading) assumptions about our community.

A few weeks ago about 10 young women attended the Living Library from a local Catholic girls school and read their way through about 10 books. Their teacher had previously attended a LGBT awareness course for schoolteachers and students that I was involved in. I got to tell my story to about 10 students, two at a time.

I was involved in. I got to tell my story to about 10 students, two at a time. It was exhausting but utterly rewarding. Some of the young women furiously and studiously scribbled notes as I spoke and others just stared with that look of young hungry eyes, eating up all this new and at times unusual information!

Book meets borrowers

It’s so powerful that the threads of our rich community tapestry meet in these unexpected ways, sharing different worlds. Essentially it is extinguishing fear and ignorance and planting the seeds of understanding and hope. If that sounds corny, I’m sorry, but it really feels like this.

One sunny winter day one of my ‘borrowers’ inadvertently became a ‘book’ himself as we volleyed our life stories like a game of yarn tennis! He had a rich and colourful life history, from LA to Nimbin and everywhere in between. At times it felt like I was the accidental counsellor and then all of a sudden I’m sharing with him deep and emotional moments of my complex life living with HIV.

I don’t really adapt my story any more than I would if I was talking to someone I met in the street. The odd tweaking, editing and age-appropriate theme/language, but other than that they can have it, metaphorical warts and all! It’s empowering to share my life and it’s an honour to have people listen and ask questions. It’s not only therapeutic, its life affirming and it makes me feel more connected to my local community – the big, wide, varied and beautiful rainbow region of Northern NSW, Australia, Planet Earth! Tobin Saunders

Tobin Saunders (aka Vanessa Wagner) is Community Health Promotion Officer at ACON Northern Rivers. He is also a Positive Speakers Bureau speaker.

The Living Library has its regular open day on the first Friday of each month from 11am-1pm at 110 Magellan St, Lismore. Tobin is usually available to be read.

Lismore Living Library: http://tiny.cc/91985
No sooner had I sat down to begin writing about my feathered obligations than the phone rang. It’s 8.15am Saturday morning and the call isn’t unexpected. “Morning, Buttercup”, I hear. The familiar voice of my country companion, with a new and unpleasant pet name.

“Is the Cluck still sitting on the eggs this morning?”

He’s asking about one of the bantam Australorp chickens that he placed 18 fertile eggs under yesterday. All going well, the beginning of spring will bring new life to our two acres in northern NSW.

My companion’s attention to the needs of our numerous poultry is unfailing. I’m amazed by his commitment to the daily routines of feed, fresh water, free (but strictly supervised) grazing time, nightly lockdown and morning release.

Four years ago when we moved to our acreage 15 minutes north of Lismore, I was quick to make it extremely clear that given the choice, I would choose not to have poultry – but my generous nature would allow them to exist on our property under his exclusive care. Thus began my now overused catchcry, “I don’t do chickens!”

Given the many pigeons, ducks and now guinea fowl that have called the aviaries and sheds in the large, fenced area in the back corner of our place ‘home’, “I don’t do chickens” is no longer a broad enough statement.

Poultry opposition

You could be forgiven for thinking that I’m less than thrilled by our extended feathered family. This isn’t entirely true. I’ll try to explain my poultry opposition. Shortly before the chicken years (BC), I lost both of my dogs within a year – one to cancer and the other to old age. I was devastated and still miss them terribly. But after 15 years of canine care (and prior to that came the Lassie the sow and Barley the lamb years in my inner suburban Melbourne backyard – a story all to themselves), I found that I was ready to embrace the reduced responsibilities that came with the loss. The potential to travel, go to a movie and dinner straight from work, decide last minute that I might have that extra drink or two and stay over at a friend’s… The feathers had the potential to take all that away.

Obviously, I have not been able to maintain my complete hands-off approach and in honesty that’s no longer what I want. I love our fresh eggs and the fact that I can share the excess with friends. I enjoy the frolicking of the flock around the garden (strictly supervised to avoid plant destruction!)

Our current rooster Juan is a very handsome Silver Duck Wing, generously given to us by a neighbour the day after our White Sussex rooster was one of the victims of the Great Fox Massacre. Juan has a gorgeous little dance for his girls, one wing down and a quick step and spin backwards. The 15 girls are of all different breeds: Leghorns, Sussex, Game, Rhode Island Red and, my favourite, Black Australorps – Australorps, apart from being an Australian-bred chicken with a calm nature, good egg production and disease resistance, have a beautiful green and purple sheen in the sunlight. Call me shallow but I want my poultry to be beautiful as well as functional. (Did I just say my poultry?! I meant his poultry. Obviously.)

Massacres

I alluded earlier to the Great Fox Massacre. I don’t want to dwell on this but I should make quick note that in the four years, there have been two massacres, one Dog and one Fox. Both of these I have been the first on the scene and the grave digger. While it is very unpleasant and upsetting, part of me comes to terms with the hunter and prey dynamic in nature. I don’t remain angry at the hunter, it is more a case of finding better means to protect the prey under our care. Guinea fowl are the latest line of defence. They set off the alarm at the first sign of danger.

The more pleasant side is checking and waiting for the new chicks to start to hatch. It’s amazing to watch. The timing is incredible. Almost three weeks to the day in the early morning the eggs will start to hatch and by the mid-afternoon they will all have emerged from the eggs and little balls of fluff will be scratching around. Mum takes great care, keeping a close eye on them for the first few months and sleeping with them under her wings.

I’d better go see if that cluck is still on the eggs and let Juan, Marcia, Buffy, Ladyhawk, Hoppy, VoVo, Guts, Cheeks, Cathy Freeman (the fast one) and the others out for a strictly supervised play in the garden.

This spring will bring new life and more responsibility – even though I don’t do chickens!

Brett Paradise

Brett supervising the chickens and rooster Juan.
Notice of Annual General Meeting and call for nominations

The Positive Life NSW AGM will be held on Wednesday, November 23, 2011, 6-8pm, at L3, ACON, 414 Elizabeth St, Surry Hills, Sydney. We are calling for nominations for the election of the Board for 2011-2012.

Nominations close 5pm, October 20, 2011.

Call Positive Life NSW on 9361 6011 or 1800 245 677 to request an information pack.

Art Phoenix
An eight-week program in Darlington in the techniques of drawing and painting.
Commencing Wednesday October 12

Phoenix Directions
Five practical workshops for people with HIV considering returning to work/study or finding alternatives to paid work.
Commencing Thursday November 10
Contact Kit on (02) 9283 8666 or email phoenix@bgf.org.au
www.bgf.org.au

Volunteer!
Would you like to volunteer at Positive Life? We're looking for people with skills in events/fundraising, accounts/general admin, archiving/indexing and also for helpers when we do magazine/letter mailouts.

Please contact Harry on (02) 9360 6011 or harryr@positivelife.org.au

Life.mail
Keeping you informed about news, events and opportunities to get involved

Life.mail is our e-newsletter – delivered to your inbox six times a year. Keep informed about news, events and opportunities to get involved in your local positive community. Subscribe at our website: www.positivelife.org.au/life.mail
Or email: editor@positivelife.org.au
Sydney positive cyclist Steven Berveling assembled the Team 4 HIV Hope to compete in the 5000km Race Across America in June. Here’s Steven’s recap of the race.

Travelling to the US for the race was a task in itself. I arrived at Sydney airport with two bikes, four spare wheels, a large box of cycling spares and bike clothing and a small suitcase of street clothes. Fortunately the airline took pity on me, minimising the excess baggage cost, after I’d told the check-in person what we were doing!

I got to California a week before the race started so that we could get together as a team. Most of us had not met before – it was great to put faces to the names of the 12 crew members and three other racers. Quickly it began to dawn on each of us that we’d be spending a week together in very close quarters, crossing the US without stopping.

The logistics of competing in the Race Across America were enormous. Not only did we all need to know our respective jobs (cycling was relatively easy; the crew’s jobs were hard and constantly changed and sleeping was set down as a job in the timetable), we also needed to ensure that all safety requirements were met. On the Thursday before the race, all our vehicles (two SUVs, one motorhome and a sedan) and all our bikes, wheels and other equipment were checked by the organisers: we were cleared to race!

Six sunrises in a day
Saturday, 18 June, 2011: We leave the motel to go to the start location. We have three hours before the start. I go very quiet: it’s taken 18 months to get us here and it’s finally happening. We’re off at 2:13pm.

During the race, we cyclists divided into two groups of two. Each group was responsible for riding the distance between two time stations along the route (there were 54 time stations, about 80-100km apart). The groups would change over at the time station, with the retiring group getting a lot of well-earned food and a little rest and the new group continuing the ride. Only one racer rode at any one time, with the second of his group being in a follow vehicle, which would then leapfrog ahead so that the racers could swap over. We swapped on average every 20-40 minutes, depending on the weather and terrain. Even so, each racer rode on average 200km per day spread over 24 hours, as fast as we could but recognising that we had a long way to go!

The race seemed really just one very long day with six sunrises, during which we raced, ate, slept a bit, raced, ate more, slept a bit less and raced, ate and slept hardly at all! We lost nearly all sense of time.

Food and drink-wise, each racer consumed about 31,500-33,500 kilojoules per 24 hours, compared to a ‘normal’ diet of about 8500-10,500 kilojoules per day. With the loss of sense of time, timing of meals was done through patterns based on the rhythm of the racing. So breakfasts and dinners could be at any time of the day or night, coupled with energy bars, gel bars and energy...
Features

The loss of a sense of time had a minor impact on taking our medications. For me, integrating them with riding proved a bit of a challenge. I take Efavirenz, which I usually take just before I go to bed. But in the race I did not go to bed, which played havoc with my perception. On the first night, about an hour after having taken them, I was riding and could not differentiate between vehicle headlights and vehicle taillights – very disconcerting when you’re on a bike. Thereafter we made sure I had a substantially longer period between taking my meds and getting back on the bike.

Showers? No time to stop; we used a lot of baby wipes. Hotel rooms? Dream on; we did not stop during the race. All the racers and crew survived on very little sleep – maybe three snatches of one to one-and-a-half hours each per 24 hours in the back of a moving, bouncing motorhome. Needless to say, we all had some low points, both racers and crew, fuelled by fatigue. (I had a small meltdown because one of my fellow racers wanted to borrow my bike's tail light – no big deal in retrospect!) But collectively we pulled each other through, with one goal in mind: get to the finish line!

We received great support from the race organisers and other teams. I managed to silence a hall of 1000 people when I told them why our team was doing the race: that many of our crew were HIV+; plus a reminder that we’re 30 years into this epidemic and that while we’re lucky, equitable access to medications remains a huge issue worldwide.

Our message was well publicised in the US media and a person living with HIV waited for hours to meet our team as we passed through a time station in a very small country town somewhere in the middle of the country. He felt unable to disclose his status in his town as it was very conservative and he perceived the stigma about having HIV as enormous. He kindly said that we had inspired him – very humbling.

Flat and brown

The scenery? There was a lot of asphalt with a white line. The California desert was just that: desert with a few rocks and occasional spindly grasses. The Arizona desert was barren with all rocks. Large cacti grew to hide the cowboys. There the crosswind (with sand in it) was 70kph for a three-hour segment: very scary but a great exfoliant. We passed through Monument Valley in the middle of the night – the rock shapes eerily lit by moonlight. But then the Rockies. We went over them in southern Colorado, at Wolf Creek Pass, which was merely 3500 metres high – about one and a half times Mt Kosciusko. Near the top, a bear crossed our path in the middle of the night. Thereafter, crossing the 650 kilometres of Kansas fortunately went quick. It is flat, brown, corn, flat, brown, corn, flat, brown, corn (you get the idea!) and with a great tailwind.

We crossed the Mississippi river at St Louis, into southern Illinois and southern Ohio. The scenery changed and became very pretty very quickly. West Virginia and Pennsylvania were pretty, but it was a major effort to climb over the Appalachian Mountains with their many steep hills and battlefields of the Civil War.

And by definition, the finish line was beautiful! Team 4 HIV Hope completed the 5000km race in six days, six hours and 34 minutes and came eighth out of the 32 four-person teams. We achieved our goal and proved that with proper medication and management, HIV is not an impediment to very tough endurance sports (or anything else for that matter) and that we can compete on an equal footing with anyone.

Taking meds

Drinks. (And I inhaled a Big Mac with all the chips somewhere along the route!)

Eating got hard for me on the second and third days – my jaw wouldn’t work and I couldn’t chew anything. So for those days I lived on gel bars and energy drinks and felt extremely gluggy. Fortunately, the jaw started working again!

Gluttons for punishment

Apart from our crew, we had Dab the AIDS Bear with us. Dab met lots of people along the way and brought a smile to them all. Dab was born as a result of a young girl who died of AIDS aged five – she could not say the word ‘Dad’ and instead said ‘Dab’. Dab spurred us on big time!

Being gluttons for punishment, we propose to compete again in the Race Across America in 2012, but with a twist. We’ve already proven that HIV+ people can compete equally – next year we will have two HIV+ riders and two HIV- riders who are HIV researchers (and avid cyclists). We propose to take regular blood samples from each of us along the way to determine the physiological impact of doing a major endurance event. So stay tuned for Team HIV 4 Hope 2012!

Steven Berveling

Look on YouTube for Dab the AIDS Bear on the Race Across America 2011.
Once your health records go electronic, will you still have privacy around your health matters? That’s the question raised by the personally controlled electronic health records (PCEHR – we pronounce it ‘pecker’) scheme the federal government is trialling in various ‘high interest’ centres, including St Vincent’s Hospital in Sydney. A significant ‘high interest’ group at St Vincent’s is the HIV-positive patient population.

There’s no doubt about the potential benefits of a reliable electronic health record. Access to detailed information could reduce consultation time, the possibility of medical mistakes and complications for patients with complex health issues. We already see the value of such electronic health databases in reducing pharmaceutical contraindications (the unwanted side effects of multiple pharmaceutical prescriptions). Electronic health records have the real possibility of improving health outcomes and quality of care for those with the most complex health needs, including people living with HIV.

Sleeper issue
What of our privacy, though? Privacy is a sleeper issue: most of us aren’t really concerned about it until it’s breached in a way we don’t like or unless we have something we don’t want others to know about – for whatever reason. HIV and HCV (Hepatitis C) remain highly stigmatised diseases that can attract discrimination, vilification or ostracism. Why wouldn’t I want the information about my HIV or HCV status kept confidential?

The PCEHR scheme brings to light issues with existing privacy protections. The PCEHR legislation being crafted by the federal government is largely reliant on existing privacy laws for its protections. Current privacy laws in NSW and federally provide inadequate protections against privacy breaches. Problems exist in both the protections and the mechanisms for remedy.

Gaps in current privacy protection laws are often located around the issue of ‘secondary’ purpose use. When information is collected from people, it may be used and disclosed for a ‘primary’ purpose, but not for a ‘secondary’ purpose, unless with your permission. At HALC, we have encountered situations where the ‘primary’ purpose has not been easily identified and so the privacy commissioner failed to find that a breach of privacy occurred, as it was unclear that the breach was for a ‘secondary’ purpose. As there is no requirement to make explicit the primary purpose of collecting information, disputes over ‘primary’ and ‘secondary’ purposes in privacy create a huge gap in protection.

Complaint and review
Under current state and federal Privacy Acts, the privacy commissioner is usually the first and last word on whether a breach has occurred. There may be no chance for face-to-face conciliation between the parties to try to resolve the complaint, as there routinely is in discrimination matters. There is no requirement for review by a tribunal or review mechanism other than court. The courts are restricted to considering only legal argument in the process and cannot determine the merits of a breach of privacy claim. Court cases over privacy issues would ordinarily attract significant costs for the losing party and so put the complainant in considerable jeopardy, effectively locking them out of pursuing the complaint.

The PCEHR will magnify accessibility of a person’s medical records and so also magnify the possibility of privacy breach or misuse of information. Where the protections advanced for the PCEHR scheme rely largely on current inadequate protections, there are real questions to be asked as to whether you will want to engage with the scheme.

While it may assist in provision of better medical care, being electronic will make access to your medical record easier. A larger range of people in the various health organisations you deal with will be able to see your record across the range of your healthcare services. While the PCHER system will allow you to set some access controls on your medical record, it will require you to take a more active role if you wish to maintain your privacy across services.

Questions remain about the amount of ongoing control you will have over your record. Once the record is activated, it will remain in the system even if you want to get out of the system. You might restrict access, but the record will be retained within the PCEHR system. There is currently no provision for you to have the record restricted upon death. This could make it hard to keep your health issues private from your executor, administrator or family after your death.

The onus on you
Where currently people rely on the direct relationship with their medical service provider to ensure their medical records privacy, with a PCEHR the onus will be on you to review and actively control your record’s access controls if you wish to maintain your privacy.

The PCEHR system will be trialled in selected medical centres, then rolled out across Australia once any bugs are ironed out. At HALC, we remain concerned that the protections and remedies for the privacy of the PCEHR are inadequate. The PCEHR magnifies the accessibility of health records and the potential for breaches of privacy. Given the potential consequences of breach of privacy and unwanted disclosure for people living with HIV (and those with HCV), the choice about whether to register for the system requires informed and careful consideration.

Legal

If you go electronic, will your health records stay private? Solicitor Brady from the HIV/AIDS Legal Centre outlines his concerns.

HIV/AIDS Legal Centre NSW
PO Box 350, Darlinghurst NSW 1300
Tel. (02) 9206 2060; freecall: 1800 063 060
E: halc@halc.org.au


There have been several recent studies pointing out how important diet and exercise are in an ageing HIV population to promote a longer and healthier road to old age and as a way of fighting off problems associated with obesity and poor nutrition. For the population in general, including many older people with HIV, overweight is a big problem, especially as we get older and lazier. One of the things that prompted me to get off my arse and start doing something about my health was observing people around me who were my age or older and thinking, ‘that is not how I want to end up’.

I brushed over diet in my first column (about exercise), but in reality exercise and diet go hand in hand, even more as we get older. It’s so easy to tweak your diet from unhealthy to healthy that I often wonder why people think it’s hard. There’s very little you have to give up in a balanced diet, though the emphasis does change from one of ‘oh, that’s too much trouble’ to one of ‘okay, I’ll give that a go’ if you know you’ll achieve positive results.

Meat-and-three-veg mentality

I’d like to think we’ve all moved on from the diet we were presented with as we grew up, especially those of us brought up with the meat-and-three-veg mentality of the ‘50s and ‘60s, though I do know of guys my age who still stick to that prescription and have never ventured outside the box. For me, the move to healthier eating occurred with the discovery of Asian cuisine. The entire Asian approach to cooking (despite being a bit preparation-intensive, though fast to cook), using all the proteins, fresh herbs, vegetables and sauces that are both tasty and healthy, appealed to me from the beginning. It’s strange how my food has changed over time, from a heavily red-meat-oriented style of cooking to a more poultry, fish and almost, on occasion, vegetarian-styled cuisine. This was never intentional, it just seemed to happen, enhanced by the new exercise regime I was putting myself through.

But – I have a severe sweet tooth. I’m one of those people who reads the dessert menu first, then decides what else to order from there. I have a weakness for potato chips, donuts, finger buns, cheese, chocolate and little cakey things from cafés. Have I given all this up in the rush for a better diet? Not on your life, though I do eat them in moderation these days. I’ve had finger buns twice this year – quite a severe deprivation for me, though I can’t say the same for chocolate. (Full of antioxidants is my excuse – I love really dark, bitter chocolate.)

What have I done to improve my eating patterns? Nothing terribly radical. To start with, I’ve never really followed diets. I did give the CSIRO diet a bash, though found it a bit heavy with protein for my evolving tastes. However, I have to say it did work and both my partner and I lost weight on it. I’m currently a fan of the Weight Watchers recipe books, available from most newsagents. I don’t follow their points system, though you can if you like. I just like their recipes, which cover everything from breakfast to light meals, main meals, dessert and snacks. There’s a heavy emphasis on vegetables, which I personally like.
What else can you do to improve your eating habits?
- Eat a lot of fresh, raw, leafy vegetables. With summer coming on, our diet will shortly go almost totally salad. It isn’t boring – there are many recipe books around now that just concentrate on interesting salads.
- Cut down on the amount of sugar and fats you use for cooking. Substitute wholemeal flour in baking; swap over to other oils for cooking, such as rice bran or grapeseed; use yoghurt and oil as substitutes for milk or cream in cooking.
- Don’t overcook vegetables – vegie cooking is one area where microwave ovens are great. Vegies should still be a bit crisp when served; grill or dry fry where possible.
- Give things like tofu a go – ignore the bad press, make decisions for yourself (though I still hate soy milk).
- Cut back on coffee and drink tea instead. Limit alcohol consumption without going dry.

All this will not cause miracles, but will be a good start and give you the impetus to trial things yourself. A good, well-balanced diet will mean that you shouldn’t have to take supplements, though it seems very fashionable to do so. It’s true that some anti-retrovirals cause depletion of certain vitamins and minerals in the body, though discuss this with a doctor or dietitian before starting a supplement regime. Don’t do things just because your friends do!

Superfoods?
Now for the big question! Do I believe in superfoods? The short answer is yes. The term superfood is used to denote foods that are packed full of nutrients. It covers the gamut from the exotic to the mundane. The latest list includes:
- Acai and goji berries (all berries are good for you and jam-packed with goodies to help your skin, brain and heart, as well as helping lower cholesterol);
- Coconut water, which doesn’t taste half bad and comes with some yummy additives these days (fashionable, especially among gym junkies);
- Probiotic cheese, though I’d rather stick to a good sharp cheddar or gooey brie myself;
- Omega-3-rich milk, though there are other ways to get omega-3, such as fish or fish oil capsules. If you do go to the gym regularly, taking these fish oil capsules can help with your heart health as well as joint protection (not to mention assisting memory);
- Maitake mushrooms, though mushrooms in general are very good for you;
- Vine-ripened tomatoes, though the health benefits of any tomato-rich diet are well known now – and how can you hate tomatoes?;
- Spirulina – this is one I’ll pass on;
- Yerba maté (a South American tea) is something I’ve tried, but haven’t developed a taste for. There is quite a ritual involved in preparing it;
- Pomegranate juice, expensive but oh so gorgeous and addictive, it’s worth going into credit-card debt for;
- And Brazil nuts, which fortunately for me come in blocks of chocolate, so yeah, I eat them.

I highly recommend you do some Internet research on superfoods, then pick out the ones you enjoy and include them in your diet.

Basic rules
So, the basic rules for good healthy eating are:
- Keep it fresh – fresh vegetables are not expensive, so stock up and learn to be creative. Use recipe books, don’t just steam and boil things – boring!
- Don’t deprive yourself of treats, just cut back on how often you have them. Keep health bars or trail mix in the cupboard for when you get those junk cravings, it works.
- If you get that ‘do I have to eat that?’ thought when you’re cooking a meal, don’t cook it. If you don’t enjoy it, you’re not going to want to eat it.
- Cut back on fats and sugar – don’t cut them out, just rethink them. Remember that fruit juices are not always a healthy, sugar-free option.
- Don’t overcook protein and vegetables – you’ll cook all the nourishment out of them.
- Shout yourself a takeaway occasionally – I go to Hungry Jacks two or three times a year.
- Don’t cut carbs and protein from your diet, your body really needs them to function properly. If like me you go to the gym early in the day, have a bacon and egg toastie after and don’t feel guilty about it. Without the carb and protein hit, you will hit the wall. You burn a lot of calories when you exercise.
- Eat as many raw vegetables as you like, they’re so good for you.
- Don’t knock frozen and canned vegetables and pulses. Most vegies are snap-frozen and are often healthier than cooking them yourself. If you buy tinned beans and lentils, rinse them thoroughly before eating.
- Look at vegetarian options, you may be surprised.
- Buy wholegrain bread instead of white. Your body needs to work to get through all those seeds, so you feel full for longer. The same with rye and malted breads.
- I still like my full-cream milk, but there are plenty of options now. Don’t get caught up with all the trendy additives in milk nowadays. These are things that are present in a balanced diet, they really shouldn’t be in milk.

Whatever you do, enjoy your food. It’s one of life’s pure pleasures. But, like sex, think before you put it in your mouth! Tim Alderman
In May this year I went to Chicago for the International Mr Leather contest, accompanying a dear friend Johnny, the current Sydney Mr Leather.

One thing that came across loud and clear in Chicago during the public events when we got to hear the contestants speak was that HIV is still with us and we need to be vigilant about the virus. Yet online, on various websites, were heaps of people there at the event, advertising for barebacking, even though a couple of years ago the management of International Mr Leather decided to ban all bareback porn and even the distributors of bareback porn from displaying any goods for sale at the huge Leather Market. (To give you some idea of the size of the market, it takes over the entire basement under the Hyatt Regency hotel in Chicago and would easily be in the region of 1.5 hectares; it runs for four days and has thousands of visitors over the course of the last long weekend in May).

It was great to be there in Chicago with my best friend in the competition. You have to be a title holder to compete at IML and there were approximately 60 men from different countries around the world. Johnny had four days of judging and I shopped – every day. I had to buy an extra case to get everything home and all I can say is, thank god for the 43kg luggage allowance.

Getting around was fairly easy and while I didn’t see much of Chicago, IML had a free shuttle bus running to events that weren’t at the host hotel, which made life a lot easier. One of the cab drivers was really great and let me sit in the front (normally a no-no in US cabs) when I couldn’t get into the back seat easily. The last night in Chicago we had a party at Excalibur. It would have to be one of the best clubs I’ve been to anywhere in the world: four floors and a smoke machine that alternatively pumps dry ice and steam onto the throbbing, heaving mass that is the dance floor. Great to watch from above (I couldn’t dance with my mobility problems and it being too soon after my last knee replacement).

The fun part

When we got to the San Francisco part of the trip – the fun part now that the work was over – it was a joy to see rainbow flags everywhere. And this is every day, not just for one month a year. And everyone was so friendly (except for one bitter queen we came across at Twin Peaks in the Castro).

While we were out at the venues I came across at least six other people who have also been through joint replacements due to avascular necrosis. [See Talkabout 172 June 2011 for Wayne’s article about undergoing multiple joint replacement surgeries because of avascular necrosis.] It seems that it is a lot more prevalent in San Francisco, mainly due to the ageing HIV+ population and the number of people who have been on meds for so long. It was great to compare notes on surgery and how we managed our recoveries, our strategies for coping with everyday life following surgery and how life changing it has been, as well as the determination to never give up enjoying life.

HIV fundraising

One thing you can’t fail to notice while in San Francisco is the HIV fundraising – it never stops. There was a huge red ribbon on the hillside over the Castro. We encountered quite a bit of fundraising activity, from performances to boys with buckets in bars to cycle rides. One of the San Franciscan contestants at IML (Mr Powerhouse) told us about entering the AIDS Life Cycle, a fully-supported seven-day fundraising bike ride from San Francisco to Los Angeles, run by the SF AIDS Foundation and the LA Gay and Lesbian Centre – 880 kilometres over seven days, averaging 130 kilometres a day. Participants are encouraged to raise as much money as they can and to seek sponsorship from anywhere they can. Their sole concern is providing critical services to people living with HIV and AIDS, so the more money raised the better. If you’re physically up for it, it’s a great way to see the countryside between SF and LA – the exact route changes every year but is always from SF to LA. To give you some idea of how large it is, this year there were 2350 bicyclists and 600 volunteer roadies and it raised just over $13 million. In 2010 it raised just over $10 million with 1903 riders. The money is badly needed, as there are over 151,000 Californians living with HIV and for the average poz person the costs associated with the condition are around US$20,000 a year.

Thankfully we live in a country where our medical needs are covered by Medicare. Apart from that, I could happily live over there and was sad to leave San Francisco, but will definitely be back – once I get the credit card bills down. Wayne Daubney
Membership and subscription form

Positive Life NSW membership

Membership of Positive Life NSW is FREE and is open to any person in NSW living with or affected by HIV.

Members receive a free subscription to Talkabout, the Annual Report and occasional email updates.

For more information, visit www.positivelife.org.au/about/membership

- Full member (I am a NSW resident with HIV)
  As a person with HIV, you are entitled to full voting rights. You must tick the Personal/Health Information Statement at the bottom of the page.
- Associate member (I am a NSW resident affected by HIV, ie, a partner, family member, carer, healthcare worker)

Note: Applications for membership must be approved by the Positive Life NSW Board of Directors. Our Rules of Association are available online at www.positivelife.org.au/links

Privacy / Health Information Statement

Positive Life NSW collects your personal information in accordance with our Privacy Policy (www.positivelife.org.au/about/privacy). Your details are strictly confidential and only used to add you to our membership database. We will send you information about Positive Life NSW and our magazine and email updates. You can unsubscribe to email updates following the instructions in the email.

We store your personal information in hardcopy or electronically or both. Access to your information is strictly limited to Positive Life staff members and will not be passed on to any other organisation or individual.

You can access and correct your personal/health information by contacting us on 02 9361 6011 or 1800 245 677 or admin@positivelife.org.au.

- I have read the Privacy / Health Information Statement and consent to my information being collected and stored.

Please return the completed form to:

Positive Life NSW
Reply Paid 831
Darlinghurst NSW 1300
No stamp is necessary.

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- Individuals
  - I am an NSW resident receiving benefits $5
    (Please enclose a copy of your current healthcare card)
  - I am an NSW resident not receiving benefits $20
  - I live outside NSW $33
  - I live outside Australia $77

- Organisations
  - Full (Business, government, university, hospital and schools either for-profit or government-funded) $88
  - Concession (PLHIV groups and self-funded community organisations) $44
  - Overseas $132

Fees and donations

Membership to Positive Life NSW is free. If you are subscribing to Talkabout, please refer to the subscription rates above.

Talkabout subscription

Donations

I would like to make a donation of
(Donations over $2 are tax deductible. You will be provided with a receipt for tax purposes.)

Total payment

- Cheque/money order (Cheques should be made payable to Positive Life NSW)

Please charge my VISA MasterCard

($10 minimum for credit card payment.)

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Tel 02 9361 6011 • Fax 02 9360 3504 • Freecall 1800 245 677
Email: admin@positivelife.org.au
### Health Promotion Fact Sheets

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The content of our fact sheets was checked for accuracy and all references to programs and contacts were accurate at the time of publication. Please note that some facts are no longer available for distribution, but can still be found on our website where we will include links to more recent or relevant information.

### Social Marketing Campaigns

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<td>10 reasons to test for STIs encourages regular testing for sexually active positive gay men. – Available on the website only</td>
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#### Positive or Negative HIV is in Our Lives

- Fact Sheet 1 Living with Risk and Taking Control: Why do we take risks? How do I manage risk and take control? If I have had unsafe sex what can I do to take back control? How do I deal with a positive diagnosis?

- Fact Sheet 2 Positive Sex and Risk: What does risk mean after a positive diagnosis? Do boundaries and attitudes to sex change? How do we think or talk about risk?

- 4 post cards with key campaign images – Available on the website only

#### Getting On With It Again

Living longer with HIV (booklet) is based on stories and interviews and shares some strategies for change and enhancing the quality of life of people living longer with HIV.

#### Get The Facts Syphilis

(booklet) updates HIV positive gay men who practice adventurous sex on strategies to maintain their health and the health of their partners. Key messages focus on transmission, the importance of testing for syphilis and strategies to prevent them from getting or passing it on to their partners.

#### KNOW THE FACTS SEX AND HEP C

(booklet) updates sexually adventurous HIV positive gay men on hep C transmission, testing and strategies to prevent them from getting or passing it on to their partners.

#### SERO DISCO

Why let HIV get in the way of a good relationships? gives gay men some practical ideas on how to look after each other in a serodiscordant relationship (where one partner is HIV positive and one partner is HIV negative). This can include everything from starting a relationship, disclosure, condoms and intimacy, relationship agreements, communication strategies, testing for HIV and STI awareness.

One-off lifestyle magazine and 4 postcards with key campaign messages.

### Workshop Resource

#### Let’s talk about it (me, you and sex):

a facilitator’s resource & workshop guide on positive sexuality. (160 pages)

#### Simple Pleasures (Workshop Guide)

Builds on material presented in our booklet GETTING ON WITH IT AGAIN Living longer with HIV. The workshop is designed to be used with HIV positive peer support groups or in HIV support groups facilitated by healthcare workers.
Men Seeking Men


Northern Rivers Mature HIV+ man. I’m affectionate, genuine, caring,fun. Likes being with a variety of any nationality to 45yo. ALA. Reply 240100

Men Seeking Women

Mid North Coast NSW. Straight, young 48yo, non user HIV+ unpartnerable in life. GOSO Definitely individual, but like us all has moments. Genuine, sincere, wants children, seeks a loving, stable, satisfying relationship. Kids OK. Desires discretion and is expected in return. Reply 130408

Mid North Coast – Someone looking for a lasting relationship with a quality mate. Sincere, caring, looking for someone sincere, caring and understand. Reply 140109

Northern Rivers. Mature HIV+ man. I’m affectionate, genuine, caring, fun. Likes being with a variety of any nationality to 45yo. ALA. Reply 240100

Leura – 44yo Pos man who recently moved to the area ISO friends and/or partner aged 35-40 for LTR. My interests include music, house, cars, cooking and movies. Reply 101110

Mid North Coast – well presented young looking 45yo, 5’11, blue eyes, cropped hair. Slim, mild build, versatile pos guy. Honest, healthy & hygienic with GOSH & interested in pets. Looking to be a friend and partner. Reply 021100

Mid North Coast – Versatile and presenting young man aged 24, 6’3, 200 lbs, blue eyes, short, straight, blue hair, medium build. Seeking a partner or friend to enjoy life. Reply 130110

Northern Rivers – Straight, young 48yo, HIV+ unpartnerable in life. GOSO Definitely individual, but like us all has moments. Genuine, sincere, wants children, seeks a loving, stable, satisfying relationship. Kids OK. Desires discretion and is expected in return. Reply 130408

North Coast – Male 46yo, tall, DTE, house, city work, good sense of humour. Reply 030110

Northern Rivers – Male 44yo, 5’9, 160lbs, non drinker, non smoker. Seeking a partner or friend to enjoy life. Reply 130110

Northern Rivers – Male 41yo, 6’1, 180lbs. Sincere, genuine, looking for a quality mate. Reply 130110

Northern Rivers. Mature HIV+ man. I’m mild to wild in bed. WTM advance/versatile. Friends with benefits. Pen pals into kink welcome. Reply 182090

Northern Rivers. Mature HIV+ man. I’m affectionate, genuine, caring,fun. Likes being with a variety of any nationality to 45yo. ALA. Reply 240100

Victoria. Youngful and energetic HIV+ guy working in Melbourne, caring, understanding, and happy to have kids sometime. Seeking to make contact with someone who accepts my HIV status and is happy to spend her time with me and enjoy life together. Reply 021109

Port Macquarie, NSW. Young 48yo guy looking for male partner. Tired of being single seeks lady wanting same. Genuine, sincere. Discernment given and expected in return. Victoria. Youngful and energetic HIV+ guy working in Melbourne, caring, understanding, and happy to have kids sometime. Seeking to make contact with someone who accepts my HIV status and is happy to spend her time with me and enjoy life together. Reply 021109

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‘Hello! Can I speak with someone who understands my culture and what it is like to live with HIV/AIDS.’

(02) 9515 5030

Translating and Interpreting Service
131 450

We can provide you with support and understanding for HIV/AIDS. Ask at this clinic for a brochure in your language. All services are confidential and free of cost.


Kami dapat memberikan dukungan dan pemahaman mengenai HIV/AIDS. Mintalah brosur dalam bahasa Indonesia di klinik ini. Semua pelayanan adalah gratis dan rahasia.