

Tales from The Network

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MEHALI TSANGARIS

Mehali works out of the Northern Territory AIDS and Hepatitis Council (NTAHC) in Darwin. As a dancer, he brings a special kind of energy and loads of charisma to a job he clearly loves. One of his clients, Carl has worked as a volunteer for NTAHC for many years. As is often the case with volunteers, Carl is generous with his time when it involves others but not so much when it comes to his own wellbeing. A while back, Carl began experiencing some significant side effects when he started on his second line of [antiretrovirals](#) [1]A medication or other substance which is active against retroviruses such as HIV.. He started finding it hard to stomach the pills, was unable to keep food down and began losing weight. Complaining of joint pain in his hips, he also found he was becoming less and less mobile. It didn't occur to Carl to take advantage of the programs on offer around him until Mehali suggested he join a Strength and Stretch class he had just set up. It took some convincing, but finally the offer of a ride to and from the session convinced Carl to give it a try. Firstly, it was the social interaction he enjoyed. The session was easy and fun and he was surprised by what he could achieve. Carl went to the next class, this time turning up early, and by the third class he started noticing that he was enjoying food more and was able to keep it down after taking his pills. By week two, Carl felt little or no hip pain and by the second month of regularly attending three classes a week he was feeling well enough to start working again – part-time, but in a job that involved physical activity. After three months, Carl took a break from Mehali's classes. Almost immediately he found it harder to eat and his hip pain returned. So, almost immediately he returned to the classes. **If you live with HIV in the Northern Territory or are a friend or family member of someone who does, you can contact NTAHC on (08) 8944 7777.**

NEIL MCKELLAR-STEWART



Neil lives in the laidback land of Lismore and works for ACON in the Northern Rivers of New South Wales. It is an area to which many people retreated in the early to mid-nineties to escape the maelstrom of the epidemic in Sydney. He likes the beach and alternative partying but he takes his job seriously — empowering people with HIV to live full and healthy lives. Neil has a background in scientific research, which is why he was particularly challenged by a call from Frank, who lives with his partner in a tropical retreat in the hills above Byron Bay. Although recently diagnosed, Frank had already embraced HIV treatments, incorporating them into a lifestyle, which included yoga, meditation, working out, natural herbs and supplements. It was in fact a supplement he was concerned about — something called Tribulus Plant Herbal Extract. Would it react with his HIV meds? But more importantly would it, as he had been led to believe, improve his muscle tone and testosterone levels? Neil's research uncovered something interesting: the Southern Cross University Department of Exercise Science (coincidentally also located in the Northern Rivers) had recently conducted a [clinical trial](#) [2]A clinical trial is a research study to answer specific questions about vaccines or new therapies or new ways of using known treatments. Clinical trials are used to determine whether new drugs or treatments are both safe and effective. Carefully conducted clinical trials are the fastest and safest way to find treatments that work in people. Trials are in four phases: Phase I tests a new drug or treatment in a small group; Phase II expands the study to a larger group of people; Phase III expands the study to an even larger group of people; and Phase IV takes place after the drug or treatment has been licensed and marketed. into tribulus, using ARL players taking that very supplement. The results weren't inspiring. They showed that taking tribulus had little effect on improving either muscle tone or testosterone. So, while it would be safe to take with his antiretrovirals, Frank decided to save his

money and focus his efforts elsewhere. **Neil McKellar-Stewart is the HIV Health Maintenance Officer at ACON in the Northern Rivers. Among other things, he runs an annual retreat for gay men with HIV. If you live in the area and would like to talk to him, call the office on (02) 6622 1555.**

JUDE O'DAY



Jude works in Hobart for the Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCAHRD) and is one of those people you meet professionally who you know would be fun to spend time with socially. She brings warmth to her job, as well as an understanding for the needs of the variety of clients she sees around the state. One of them, Nic, mentioned over several conversations how depressed he felt and how debilitating this depression was becoming. Things at work were difficult and he had issues at home, but even when these things improved he found the depression still lingered. Jude and he discussed his HIV treatments and their side-effects, highlighting efavirenz as one component that might be exacerbating his condition. They also talked about antidepressants, something which Nic initially ruled out as an option. He was also reluctant to broach the subject of his depression with his doctor, afraid that changing the regimen he was currently on would have a devastating effect on his health. It was only through regular chats with Jude that Nic developed an understanding of the treatment options open to him as well as a confidence which enabled him to approach his doctor. Nic is now trialling a new antidepressant, with the promise that if that doesn't work, a change in antiretrovirals can easily be considered. He has also agreed to ongoing counselling with a psychologist. Importantly, he is happy with these choices. **Anyone with HIV in Tasmania can contact TasCAHRD on (03) 6234 1242.**

MAHAMATI



Mahamati has worked in care and support around the country for many years, most recently in Adelaide for PLWHA SA. She is somewhat of a sage in the sector. Leon first made contact with her by email. There were in fact quite a few emails. He wanted to make sure no other Africans had appointments the day he came in as he didn't want to be seen — fearing discrimination if his status was known to others from his country. Here on a student visa, Leon's health had deteriorated over the past six months and he had been advised to start treatments. He had many questions about treatments and was particularly worried about how much they would cost. He did not plan on staying in Australia, so it was also important that the regimen his doctor devised would be available when he returned home. When he did finally come to visit, Leon was surprised with all the help Mahamati could offer. She linked him up with the Special Needs Clinic for some badly needed dental work. He was able to supplement his income by shopping at their HIVE food pantry. He even considered trying a massage one day. His doctor put him on an appropriate combination and Mahamati was able to access funds to help pay for his medications. When he experienced side effects he emailed her for reassurance and when

he transferred his course interstate she was able to link him up with positive services in that state. **If you need referral to HIV services in South Australia, contact PLWHA (SA) on (08) 8293 3700.**

NADA RATCLIFFE



Nada sees a variety of clients come through her doors in Canberra, many of them new to the territory. Helen was one these. A woman in her sixties with strong Christian beliefs, Helen had relocated from a regional community to Canberra following her diagnosis. Plagued with feelings of shame and guilt she was finding that even the act of taking her pills was too much and was considering stopping treatment altogether. Her doctor changed her to a simpler regimen and referred her to Nada who suggested she might like to meet other positive women. At first, Helen was very reluctant to become involved, concerned that she would not fit in. The impressions she had of people with HIV was still affected by those she had prior to her diagnosis. Finally, she did attend a social evening and was thrilled at being able to discuss her feelings and experiences with other women. Nada also arranged for her to meet with a registered nurse who provided some practical advice to deal with the problem she was still having with her antiretrovirals. It has been a difficult transition but through counselling and peer support, Helen is slowly learning to deal with her feelings. **Nada Ratcliffe is the Manager of Community Support Services at the AIDS Action Council in the ACT. If you are HIV positive or close to someone who is and would like to talk to Nada, call her on (02) 6257 2855.**

JENNY MCDONALD



Jenny is a Melbourne-based dietician who has specialised in helping people with HIV for over twenty years. One of her clients, David, recently started a new treatment regimen which included a small dose of ritonavir as a boosting agent. Almost immediately, he started suffering from diarrhoea and consulted Jenny for advice. She has seen many people in this situation and advised David to approach the problem two ways. The first was dietary. He agreed to increase his fibre intake at breakfast by eating oats — in porridge or in muesli — topped with yoghurt and a teaspoon of psyllium husks (found in Metamucil). He also agreed

to avoid spicy and fatty foods and to increase the amount of rice he had for dinner. Also, because he suffers the diarrhoea first thing in the morning, he agrees to take an Imodium tablet at night. (If he suffered it at night, Jenny would suggest taking the tablet in the mid-afternoon.) It takes a few weeks for David's gut mucosa to regenerate. But he's happy with the improvement and soon finds that the dietary changes alone are enough, and is able to ease off using the Imodium. **Jenny McDonald works out of Melbourne Sexual Health Centre and Prahan Market Clinic. She also regularly visits Canberra and Darwin.**

LAURA JONES



Laura is the General Manager for the New Zealand AIDS Foundation and currently divides her time between their offices in Wellington and Christchurch. When William first came to see her, he was adamant that he would not go on treatments, deeply suspicious of the drugs and their potential side effects. He had been using [alternative therapies](#) [3]A broad range of healing philosophies, approaches, and therapies that Western (conventional) medicine does not commonly use to promote well-being or treat health conditions. Examples include acupuncture, herbs, Traditional Chinese Medicine, etc. but despite this his CD4 count had been slowly and steadily declining and he was fast approaching a level where he was at risk of developing an Opportunistic Infection (OI). William agreed to work with the counsellor Laura introduced him to, and together they explored the issues behind his reluctance to consider ART. Along the way, he also joined a smoking cessation program that he had been considering for some time. Additionally, couples counselling and separate sessions with his mother helped William work through some of the things that stood in the way of him accepting the need to start treatment. Things have moved on, and he is now more open to the option of treatment and in the meantime a compromise has been reached where he is taking prophylaxis to prevent him getting any OIs in the short term. **If you live with HIV in New Zealand and would like to discuss anything with a support worker at the NZ AIDS Foundation, you can call them in Wellington on (04) 381 6640, in Christchurch on (03) 379 1953 or in Auckland on (09) 309 5560.**

PETER WATTS



Peter works for Queensland Positive People in Brisbane and has a real interest in supporting people who are experiencing symptoms of HIV and the side-effects of treatment. One of his clients, Julie, has been dealing with a persistent rash for some time. Unfortunately, despite the many treatment changes Peter has guided her through, the rash persists. It makes it hard for her to get out and about, so Peter is staying on the case, regularly checking up on her progress and working with her doctor to try and isolate what the cause could be. Outside of treatment-specific work, people come to Peter for immigration and travel advice, and now and then some pretty astounding cases of discrimination. Others seek support for daily living needs such as employment, but most people seek him out as a friend with a listening ear. 'Each worker in the network has a different set of skills to offer so, collectively,' he says 'we support the entire nation with a really broad set of knowledge.' **Peter Watts is the Health and Treatments Officer at Queensland Positive People (QPP) in Brisbane. You can call him on (07) 3013 5505.** Other members of the network, whose tales we will tell in upcoming issues, include:

- **Cipri Martinez**, HIV+ Peer Educator and Support worker for the Western Australian AIDS Council (WAAC) in Perth. **His phone number is (08) 9482 0000**
 - **Jae Condon**, Treatments and Client Support Worker at the Positive Living Centre, ACON in Sydney. **His number is (02) 9699 8756.**
 - **Vic Perri**, who does general health promotion at PLWHA (Vic) in Melbourne. **Call him on (03) 9865 6772.**
 - **Michael Riches**, the Team Leader of Client Care Services at the Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC) in Melbourne. **You can contact him on (03) 9865 6700.**
 - **Merryn Kellie**, the HIV Care and Support Officer at the Northern Territory AIDS and Hepatitis Council (NTAHC) in Alice Springs. **Her number is (08) 8953 3172.**
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- [living with HIV](#)
 - [Accessing HIV care and treatment](#)
 - [Treataware](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/122>

[2] <http://www.napwa.org.au/glossary/term/89>

[3] <http://www.napwa.org.au/glossary/term/478>

