

NZ AIDS REPORT

Think positive

Antiretroviral treatments can stop HIV advancing to Aids, but last year more Kiwis were diagnosed with HIV than ever before. BY SARAH BARNETT

A series of unexplained illnesses four years ago led Rhys Jones, then 22, to add an HIV test to the other blood tests he was having done. These days, results can be returned within 10 minutes. Back then, he faced a 10-day wait: "I went to Wellington for a few days, and when I got back, my doctor had left me 15 messages. So I knew."

His dad drove him to the clinic to get his results, and Jones told him the moment he got back in the car. "We went home and Dad googled it straight away."

Even though the average person on the street would have a fair idea of what's involved in treating, say, breast or prostate cancer, medical care for HIV-positive people remains a mystery to those unaffected by the disease.

The epidemic that caught the nation's attention just 20 years ago has all but disappeared from view. The management of HIV/Aids in New Zealand could be one of the country's great public-health success stories – we have some of the lowest rates in the world, and almost no HIV among drug users and sex workers – yet the flip side of that is the disease's near invisibility now, even as infection rates climb.

In March, the University of Otago's Aids Epidemiology Group released its latest statistics, showing that 184

people were diagnosed with HIV in New Zealand in 2008 – beating the previous high of 183 in 2005.

More than 670 people have died of Aids in this country; at least 2700 people live with HIV now; and despite three new infections a week, New Zealand Aids Foundation (NZAF) executive director Rachael Le Mesurier says that "there's a sense of complacency that things are okay now".

Jonathan Smith, a former chairman of the NZAF, was diagnosed 15 years ago.

He says the success of antiretroviral treatments, which prevent HIV from advancing to Aids, thus making HIV a chronic, rather than a fatal illness, is a mixed blessing.

"You have to be very careful about the way you talk about that in public," says Smith, "because you're sending a dangerous message. It's like saying, 'You don't need to protect yourself, we can deal with it.'"

Smith is creative director of the Queen of the Whole Universe pageant, which he hosts as his alter ego, Bimbo. His biggest challenge "was going through that psychological shift from thinking about my mortality rather than thinking about longevity, which is the way I'm now thinking because of new medication". Appearing onstage with his partner, who does not have HIV, is Smith's way of putting a face to the



Younger guys find it harder, if a test is positive, to be open about their HIV status.



Not hiding: HIV-positive Rhys Jones (second from right, and below left).

disease, and raising more than \$100,000 for the NZAF.

Rhys Jones has not gone onto treatment yet, though he has had to make major lifestyle changes – "no more big nights" – and his viral load has to be carefully monitored. He will be given a treatment regime if it reaches a certain level.

The side of the treatment the community doesn't see, says Smith, is "how much diarrhoea and nausea and liver problems you might have". Then there's the pressure of being fully compliant with a drug regime, at the risk of building up resistance and needing different drugs that may not be available, or funded. "The obvious [side-effect], the visual one, is wasting, lipodystrophy," but procedures to fill out skin, particularly in the face, are now available (the NZAF has grants to pay for it). "It's great for self-esteem, you're out there, you're feeling better. But the rest of

the community is now thinking, 'I'm not seeing people ill anymore.' So it's like a double-edged sword. You've got medications to keep us well, and cosmetic procedures for some of the visual side-effects, but you're also sending a slightly different message. It's a bit scary for me."

Twenty-one-year-old Josh Chapman, who was the NZAF's "poster boy for safe sex" last year, says that he has talked to "older guys in the community about what it was like to grow up before homosexual law reform" and "things have changed drastically and for the better", but he echoes the concern about attitudes towards the risk of catching a disease that may no longer be fatal. "The fact is that because these HIV meds are available, people aren't dying as in your face as they were in the late 80s and early 90s. So that's the whole 'it's never going to happen to me' scenario."

Despite three new infections a week, "there's a sense of complacency that things are okay now".

Chapman's mother, Beverly Hobman, works in healthcare, and says "you don't come across many HIV-positive people at all, and people think it's gone away", yet she knows better than many how close to home it can come. Her husband Bryce – Chapman's father – died of Aids in 1984. "He was in denial, in those days," she says. "I've got a feeling there are still men out there who are in denial."

She, too, worries about whether young men are taking responsibility for their health – "they're pretty loose and they've all got alcohol in their hands" – but sees it as a parent's responsibility to give kids "a

basic knowledge of how to take responsibility for your own health ... you don't bring them into the world and then kick them to the curb".

It's great, she says, "to imagine that [Josh] does have a future, that he won't get taken out by HIV, like his father did", because he knows about prevention.

The safe sex message is lost, though, and not just among the gay community: New Zealand has the second-highest rate of teen pregnancy in the OECD; chlamydia and gonorrhoea rates rose by 19.4% and 55% respectively between 2003 and 2007.

UK Aids epidemiologist Elizabeth Pisani says that talking about the downside of the success of treatment isn't just difficult, it's "heretical", and fears that the experience of gay men in the developed world, among whom infection rates have climbed in recent

years, will be mirrored in the developing world, as treatment becomes more available and HIV-positive people live much longer.

"We prevent Aids – because that's what treatment does, it prevents Aids – but it doesn't prevent HIV. We're already failing miserably at preventing HIV when it's a fatal disease, but what do we know about preventing it when it's not a fatal disease anymore?"

Her answer is "not very much", and Le Mesurier echoes that. "[HIV] is something that human beings are going to have for a very long time, so the impacts of the types of treatments that we've had that have been very successful in suppressing it – we've never really understood what that would mean around behaviour.

"Getting the treatments is not the holy grail – in fact, it's just stage one. Stage two is, how do you work with the populations who, after the treatments, may change their behaviour because the treatments have taken the death away?"

Prevention is an entirely different story when the risk profile of the disease has changed. Says Pisani, "Among drug injectors, we haven't seen people say, 'Oh well, now it's not fatal anymore, I'm going to go back to sharing needles.' The fact is, no junkie wants to share a needle any more than you want to share a toothbrush ... whereas people do want to have sex without condoms, simply because it's more fun to have sex without condoms."

If treatment is not the holy grail, getting a vaccine has long been regarded as such.

Do a search for "Aids vaccine" and the internet pours forth pages of historically misplaced optimism. Headline after headline going back as far as 1984 promises "new hope" for a vaccine that is "in sight"; "within five years"; "on the horizon"; "by 2005".

Pessimism is starting to take hold. The *Independent* surveyed 35 HIV/Aids specialists in the UK and the US in April last year, and found that only two of them were more hopeful about a vaccine than they were a year previously. Two-thirds doubted the holy grail of Aids research would be discovered in the next decade, and some said they found it improbable that a vaccine would ever be developed – and if it were, it would be unlikely to be fail-safe.

In 2007, pharmaceutical giant Merck called off what had been one of the most promising trials on human subjects after determining that not only was it ineffec-



From left, Buffy, John Key and Bimbo at the Big Gay Out festival in Auckland, February 2009.

"Medicine is getting better and better but the virus is getting cleverer and cleverer."

tive, but volunteers may have been made more susceptible to contracting HIV. It had been successful in trials on monkeys, meaning that the efficacy of what had been standard – monkey trials before humans – also came into question. In July last year, a trial of a US government-developed vaccine was stopped before it even began, as officials worried they didn't yet know enough about why the Merck trial had failed.

Nobel-winning biologist David Baltimore added his voice to the chorus of lost hope in an address to the American Association for the Advancement of Science in February, saying, the *New York Times* reported, that HIV had evolved in a way that made it impossible to attack – leaving, he said, "no hopeful route to success".

And this is hardly for want of money: until 2000, there had been around 60 clinical trials for potential vaccines; currently, there are over 80 taking place worldwide. Between 2000 and 2005, US\$682 million was spent each year on the quest for a vaccine – which seems destined always to be on the horizon.

By world standards, New Zealand's history of HIV/Aids prevention is commendable. "We are one of the most successful [countries] in keeping HIV prevalence very low," says Le Mesurier, thanks in part to a pragmatic response by government, but also largely due to the actions of those communities at risk.

QUEEN OF THE WHOLE UNIVERSE, St James Theatre, Wellington, June 27: www.queenwholeuniverse.com

Homosexual law reform was introduced in 1986 and clean needle exchange programmes in 1988, while sex workers formed the Prostitutes' Collective and kept HIV out and STI rates remarkably low in the Kiwi sex trade. It was a "phenomenal" achievement, says Le Mesurier, not least because it happened in a criminalised environment. "It is held up worldwide as a remarkable success story that we don't have HIV among our sex workers."

Yet, Smith notes drily, "The fact that [homosexuality] is legal doesn't make it any easier." It's still hard for young people to come out, he says, after more than 20 years.

Even after all this time, Le Mesurier reiterates, what makes preventing HIV an uphill battle is discrimination and stigma. Hobman's family heard the gossip buzzing in their rural town when Bryce was diagnosed, yet while attitudes may have changed for the better, Chapman says he's still aware of bullying in schools. Jones says younger guys find it harder, if a test is positive, to be open about their HIV status. Now, he says, because he has made appearances on TV and in other media representing Body Positive, a support group associated with the NZAF, "young guys are coming straight to me".

Surveys of HIV-positive people show how isolating the disease can be. HIV Futures New Zealand is a project led by the Australian Research Centre in Sex, Health and Society at La Trobe University, Melbourne, in collaboration with NZAF, and is the comprehensive study of HIV-positive people in New Zealand. The most striking thing about the results of the second survey, undertaken in 2006/7, is that there are very few universal answers to the questions asked: the experience of being HIV-positive is different for every one of the respondents. Over half of them reported that they didn't even know another HIV-positive person.

Says Le Mesurier, "there's the complexity of the success [of the treatment] – as in, people aren't dying. People who were dying knew of each other because they were in the infectious diseases ward together."

Pisani says antiretrovirals may not stem the tide forever, given the costs of treating HIV-positive people for, perhaps, decades; the social issues of disclosure with sexual partners; and the lifestyle impact of following a treatment regime. "Medicine is getting better and better but the virus is getting cleverer and cleverer. And so we're sort of running to stand still." ■