

David A. Cooper
UNSW Town & Gown dinner, Leighton Hall, Scientia
Monday 24 October 2011

Good evening. Thank you for that kind introduction. Some of you may not be familiar with the name of my organisation, the Kirby Institute, but you might recognise our previous title, the National Centre in HIV Epidemiology and Clinical Research. We changed that long and clunky name earlier this year to the Kirby Institute, in honour of the Hon. Michael Kirby, who is a long-time warrior for health and human rights. Because the field of blood-borne viruses far too often intersects with issues of discrimination, poverty, gender and disempowerment, it is unwise, in fact impossible, to work in this field of infectious diseases without acknowledging the human rights aspects. We will soon have new premises on the UNSW main campus to go with our new identity. We are grateful to the university, state and Commonwealth governments and to our major donors, especially Atlantic Philanthropies, for giving us the opportunity to move to the Wallace Wurth building redevelopment on the corner of High and Botany Streets. It's going to be a wonderful environment for our researchers and we are looking forward to it immensely.

My own area of research, broadly speaking, concerns HIV. The Kirby Institute also works in viral hepatitis, other sexually transmitted infections and Indigenous sexual health. Tonight I could sketch for you a picture of my research. But instead, I'm going to tell you about the patients and the volunteers for our clinical studies, the ones who become our friends as well as our advocates in their own communities.

In particular, I'd like to speak about my friend David Polson, who has generously allowed me to talk about him tonight. I have been his HIV physician for more than 20 years and I am honoured to be allowed to call him Polly. It was Polly who has left me in no doubt over the years that the life-saving HIV drugs I had given him have had vile, really appalling side-effects. It was Polly who marched into my office a few years ago and pulled up his shirt to show me a disfiguring side effect called lipodystrophy, or on another occasion to dramatically announce his intention to abandon all HIV medication because of the endless nausea, fatigue, vomiting, tingling of lips, peripheral neuropathy, migraines and other unbearable effects of the drugs. In fact, I would like Polly's story to be heard by every young person at risk, who has come of age believing that HIV is nothing to worry about any more – they think the pills will be enough. To them I say, yes we have treatments but no magic bullets.

I first met Polly in 1989. We use a key blood marker for HIV, called CD4, to determine the strength of a person's immune system. Polly's CD had recently dropped dramatically and I gave him the first of his many HIV drugs, in fact the only HIV drug we had then, called AZT. He soldiered on through the side-effects, and for the next twenty years he kept soldiering on through increasingly ugly side-effects as the single drug therapies came along one by one.

But he continued to volunteer for clinical trials, which are the essential key for us to understand which treatments work best in which circumstances. These clinical trials over 25 years led directly to the development of combination therapy, one of the miracles of modern medicine now responsible for saving literally millions of lives around the world. It is fair to say that these clinical studies have been the rock on which our successes in HIV and more lately in viral hepatitis have been achieved, and without these studies, and our willing pool of volunteers, we as a community would have seen a great deal more infection, illness and death.

Polly himself has thought about this over the years and I think he is representative of the many hundreds of people who have volunteered, when he says that he's about 50-50: meaning that half of his motive in volunteering is to benefit from the new drugs, and half of it is altruistic, hoping that his participation will help the community and medical science even if it didn't help him. All the while he was coping with side-effects while doing his job as national training manager for a major hotel group, flying around Australia and managing the strict timetable to take the drugs.

Polly is 56 now and has lived with HIV disease for almost half his life. Our drug treatments have kept him alive, kept him at work until recent years and kept him active. The combination therapy of multiple drugs, with much lower side-effects, works well for him as long as he takes his 42 tablets every day. But these 42 tablets tell another story, because they are not all for HIV. Combination therapy is so effective for HIV, and keeps people alive for so much longer, that we find ourselves in a challenging new era of HIV treatment. Long-time HIV patients now present with premature ageing, chronic drug toxicities and other co-morbidities, including heart disease and cancer, at rates higher and earlier than in the general community.

In Polly's case, his HIV treatments have caused heart disease and a very rare brain disease which will increasingly disable him. But Polly is the most positive person you could meet. He's not complaining. "That's life," he says. "There are people worse off than me. Think of all the beautiful people who are long gone."

Usually the medical staff are the ones to enrol people into our clinical trials, but sometimes patients actively seek out the opportunities. One patient who has participated in several clinical trials including one which finished in 2008, and he keeps asking one of my colleagues, "Do you have any clinical trials suitable for me?" When she quizzed him on what it was that he gained from participation, he said, "I feel connected with what's happening with the field when I participate in a trial, I feel up to speed with the cutting-edge science and it makes me feel that I am part of something bigger, a more global purpose even if I don't personally benefit."

Another patient, who became HIV-positive three years ago, said he wanted to start treatment as part of a clinical trial because he felt that the research question was important and that he liked the fact that the results might benefit HIV-positive people in the developing world.

We have also had volunteers into our viral hepatitis trials: they are a different generation, with different attitudes but similar motivations to Polly's. A young woman, who enrolled in one of our cohort studies in South West Sydney came from a very deprived, difficult background with a long history of heroin use and imprisonment. With our support – and a lot of hard work on her part – she has turned her life around, making a successful transition from participant to professional. We helped her to get treatment for her drug use and she began studying at TAFE to complete her secondary schooling. From there she completed her undergraduate degree part-time while working on one of our projects. Last year she received a master's degree from UNSW, and she continues to work in the field.

Sometimes we are able to actively incorporate peer-based support in the viral hepatitis treatment clinic sites. One unemployed client, who was receiving methadone at a clinic, started a part time job providing peer-based support to other clinic clients. He has been so successful that he now has a full-time position in an expanding peer-based support project. He also won a scholarship (that we created) to attend an international conference on Hepatitis Care for Substance Users in Brussels last month and he gave an oral presentation on his work.

Our connection to all of these people has come about through the happy accident of being located for 25 years on the St Vincent's campus in the heart of Darlinghurst, where the gay community, the sex worker community, the injecting community, have all coalesced around the hospital. The long and fruitful partnership between St Vincent's and UNSW has been the basis of all we have achieved, and after the Kirby Institute moves to Kensington, we hope to establish a dedicated clinical research facility, where we can provide both health care and the opportunity to volunteer in our clinical studies. Our success is not only from our world-class research but also from our local connections. My researchers and I may be the **Gown** for our patients and volunteers, but these people are very much our **Town**. Thank you.