

## Conference 2005 – opening plenary

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Below is the full text of the opening plenary address to the 2005 NAPWA Conference, delivered by Ian Grubb on Saturday November 19.

Good morning, and thank you very much. It really is an honour for me to be invited to speak here today. I have to sincerely thank John Daye, Jo Watson and David Menadue – who first approached me – as well as Gabe and Rodney and the NAPWA Board and Nicola and Scott and all the organizers. Thank you for honouring me with this invitation. It's particularly great to be herein Adelaide, a city which I last visited as a 3 year old, well, quite a long time ago.

This is a great opportunity for me, firstly to wax a little nostalgic, and to reflect back on the last time I attended this conference, in Sydney, back in 1996. Secondly, having found myself smack in the middle of the World Health Organization's global campaign on antiretroviral treatment for the last 4 years, I'll share with you this morning some of my experiences, particularly as a person living with HIV, in the rather bewildering highways and byways of the UN bureaucracy. My main message to you today will be that, although the HIV epidemic continues to sew havoc, especially in Africa, and there is still a long way to go, as access to treatment expands globally, there is finally some reason for the global community of people living with HIV to feel the same sort of hope that we here in Australia felt back in '96.



It's actually 11 years now since I first attended this conference, back in 1994. I had been diagnosed with HIV just a few months before, and when I wasn't actively pursuing my new goal of partying myself to death, I was working at [AFAO](#) [1] Australian Federation of AIDS Organisations. AFAO is the peak non-government organisation representing Australia's community-based response to HIV/AIDS. AFAO's work includes education, policy, advocacy and international projects. as the first national PLWHA policy officer. Like everyone else at AFAO at the time I spent half my day drooling over the editor of the National AIDS Bulletin, Derek Hand, and the other half trying to keep the NAPWA co-presidents, Andrew Morgan and Geoffrey Harrison, from killing each other. Whoever came up with the idea of having co-presidents was really stupid! The '94 conference was my first exposure to national PWA issues and it's worth pausing to remember that, not only had none of us ever sent an email, but, more to the point, with prophylaxis and monotherapy our only real treatment options, friends and colleagues were still dementing, flaming out, having their last dance and otherwise dying right around us. Most of us nursed the touching but fairly unrealistic hope that we might live to see the Sydney Olympics.

Two years later, in 1996, I again found myself on the organizing committee of this conference and by then, of course, the picture was altogether rosier. This was, incidentally, probably the heyday of the Australian response, when everyone from commonwealth health bureaucrats to little old ladies on the street spoke reverentially of "The

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Partnership”: a national, consensus-based, stakeholder-driven collaboration on HIV/ AIDS. I’m led to believe that things have changed markedly in Australia, and that, lamentably, the much admired Partnership is in some respects a shadow of itself. Then, it seemed, Australia’s response was the envy of the world. What we needed more than anything, was better drugs. HIV drugs, that is.

Lo and behold, in ‘96 at the Vancouver international AIDS conference, almost like manna from heaven it seems in retrospect, the drugs came. Those of us lucky enough to be there won’t forget attending David Ho’s late breaking session on the last morning of the conference. The aisles were packed with people sitting and standing and falling over one another, and the energy was probably more electric than at any AIDS conference session before or since. What we heard from Ho was that – rather than lounging about for 10 years as we had thought – the [virus](#) [2]A small infective organism which is incapable of reproducing outside a host cell. started to do its dirty work from Day One. All the exciting new [clinical](#) [3]Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. data about protease inhibitors and triple [combination therapy](#) [4] Highly Active AntiRetroviral Therapy ??? aggressive treatment of HIV infection using several different drugs together., he told us, held out the tantalizing prospect that with enough time on a potent triple regimen, perhaps just a few years, we could eliminate HIV from our bodies.

So there it was, clear as the skies over Vancouver – the cure was just around the corner! That’s what it felt like. And, Ho was telling us that there was no time to waste. The sooner we started getting those pills into our bodies, the quicker the virus would be gone.

It’s no wonder that for the 1996 NAPWA conference, just three months later, we decided on the theme, “Turning Point”. At the conference, this time in the Gazebo Hotel in Potts Point, we heard from Martin Delaney at Project Inform about hitting hard and hitting early. Delaney took us into the realm of what seemed like science fiction by telling us that soon we’d all be measuring the amount of virus in our blood, and the amount of drug, and using genetic tests to see if we were developing [resistance](#) [5]HIV which has mutated and is less susceptible to the effects of one or more anti-HIV drugs is said to be resistant., and suddenly it all seemed a hell of a long way from vitamin C infusion and Bactrim and “living positively” and sending your steak back to the kitchen if it wasn’t properly cooked.

‘96 was a turning point in other ways too. We had indigenous people living with HIV at the conference in significant numbers for the first time, as well as some PWA from Asia. As if all that excitement wasn’t enough, sometime between the opening reception at the Midnight Shift and the next morning’s opening plenary I had gotten to know one of the other conference speakers rather better. For those of you who made a new friend last night I’m glad to report – with a few family snaps – that conference romances can last, and nine years later, just last August Craig and I got married near Toronto. So, thanks are definitely due to NAPWA for finding me a fabulous husband.

A few weeks after that conference, I went on treatment, and as a great believer that if something aint broke, don’t fix it – I’ve stayed on treatment ever since. I’m still waiting to eliminate the virus, I suppose. Some people haven’t done as well as me, it’s true and for a lot of people it hasn’t been easy. But, against all our expectations, many if not most of us have indeed survived, and Olympic buffs like Russell Westacott have already booked their tickets for London in 2012.

To me, it’s also a miracle that I’m here. When my doctor in Geneva recently gave me what amounts to another clean bill of health, I said to him, “You know, I really don’t believe that these results are so good after all this time”. He just looked at me and said in his rather stern Swiss way “Well what’s not to believe? If you take your pills, there’s no evidence that they stop working at any point.” And so this morning I took my nearly 7000th dose with the sense that I am much more likely to be knocked over by the great [flu](#) [6]A highly contagious and relatively common viral infection of the respiratory system, transmitted by infected droplets of moisture which may be spread through coughing and sneezing. Most people with flu recover but some go on to develop secondary infections such as pneumonia which may be fatal. pandemic of 2013 than to die of AIDS.

My point, here, is that, while I feel immensely fortunate to have had reasonably good treatment and care for nearly a decade now, I’m reminded constantly in my current work that my own good fortune is little more than an accident of birth.

We’ve all seen slides like this one a gazillion times. In the very dark little red countries here, Lesotho, Swaziland and Botswana, every third or fourth person has HIV. In the larger towns and cities in these countries, it’s every

second or third person. And these are countries that barely have rudimentary health systems, let alone HIV treatment. Here's a typical hospital, in Botswana, a rich African country. Uganda, with 5% HIV prevalence, has one doctor for every 18,000 people. Malawi has one working microscope per 100,000 people. The first time I went to a poor African country, Uganda, all the businesses on the road between the airport and downtown Kampala were coffin shops. I couldn't tell to what extent that was sort of "normal" – you know, maybe it was just the Coffin District – but I feared otherwise. So, as you see here, while rich countries have benefited incredibly from treatment, about 8,000 people have continued to die of AIDS every day, the vast majority of them Africa. Until recently the world has always sort of helplessly accepted that in the natural order of things, because HIV drugs are so expensive, we will live, and they will die.

Four years ago, I was living in Canada and my main concerns were not people dying in Botswana but surviving another 7-month winter and wondering, as a Board Member of the AIDS Committee of Toronto, whether Phillip Morris – owner of the Marlboro Man – was going sue us for the ridiculous – and ridiculously successful – Condom Country campaign. Suddenly, for me, as they say in Canada when life takes an unexpected turn, everything turned on a dime. I was visiting Melbourne for the [ICAAP](#) [7]International Congress on AIDS in Asia and the Pacific. – the regional AIDS conference – and was out having a Marlboro when I ran into Michael Bartos. Michael was a former President of VAC and at that time was living in Geneva writing speeches for Peter Piot, the director of the [UNAIDS](#) [8]Joint United Nations Programme on HIV/AIDS. UNAIDS is the main advocate for accelerated, comprehensive and coordinated global action on the epidemic. program. Michael asked me, half in jest, if I was interested in a policy job going on the WHO AIDS program. I didn't know really what he was talking about. To be honest, the idea seemed nearly as ridiculous as Condom Country. Craig and I had just spent 6 months gutting our house in Toronto. We liked the new colour scheme. I certainly didn't know anything, or not very much, about global AIDS policy.

It was at that moment that I recalled the words of Bill O'Loughlin from some years before, when Bill had encouraged me to apply for the NAPWA policy job at AFAO. I remember saying to him "But Bill I don't know a bloody thing about policy. I don't even really know what policy is". Bill gave me a wonderful piece of advice: "Look", he said, "Policy is writing down whatever makes sense to you. If you don't know what makes sense", he said, "there's usually a brochure on it somewhere." And for the most part, Bills has been right. There usually is a brochure or something on most topics somewhere, and one of the tricks of doing policy work is to master the art of cut and paste. If there isn't a brochure on a topic, though, a good approach is to write down whatever seems to make the most sense. The way you know you're having an influence on policy is when you see that others are cutting and pasting your brochures. And so it goes.

To cut and paste a long story short, having followed a man I hardly knew to Canada for love, moving to Geneva for a job didn't seem that much of a stretch. Two months after that smoko at ICAAP, we had moved to Geneva and I found myself working for Bernard Schwartländer, then the Director of the WHO AIDS program.

As it happened, about six months before I arrived, Schwartländer had published this now quite famous article in Science for the first ever UN General Assembly on AIDS. The article – which is really just a theoretical costing model – estimated that that if the world coughed up about \$10 billion a year, it could do all the things that the General Assembly was debating at the time and – at no extra cost – treat three million people living with HIV/AIDS by 2005. That was the first time someone had put a price tag on an comprehensive response to the global AIDS epidemic. It was the information Kofi Annan then used to call for the creation of a global health fund. Bill Whittaker helped to draft the Declaration of Commitment from that General Assembly on AIDS. He will know that the Assembly failed to endorse a global target for treatment – mainly because nobody really believed that treatment was feasible in poor countries. This was the time when most people – particularly the big donors – were still saying, well, treatment isn't cost effective, you're better off focusing on prevention. Apart from the fact that this argument quite jauntily condemned millions of people to death, we now know for sure what we suspected then, that just doing prevention or just doing treatment is nowhere near as effective as doing both together.

So, the task for Schwartländer and the team that I joined at WHO in early 2002 was to try to change the paradigm, to build the case for treatment, to bring an end to the double standard which said that the rich may live but sadly the poor will die.

And even though WHO was actually in quite an organizational mess at that time, we realized that the one thing we could do was to use the incredibly powerful moral voice of the organization to make the case that treatment was as essential a part of the response – along with prevention and everything else – in poor countries as well as in rich ones. Basically, for the next two years, we did advocacy, both internally at WHO and externally with countries, with

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donors, in the media, with anyone who would listen. We did that in lots of different ways:

- We turned this idea of getting 3 million on treatment into a rallying cry, to say, if we spend enough money and train enough health care workers and fix the drug supply systems, if we all work together – big ifs, to be sure – we should be able to increase the number of people on treatment from about 300,000 then to 3 million people by the end 2005.
- We also said that treatment was something that all countries needed to include in national health plans for AIDS. This was an important global health sector strategy document written in 2002 for WHO in large part by Bill Whittaker that talked really for the first time about treatment as an essential intervention in all countries.
- We lobbied successfully to get [antiretrovirals](#) [9]A medication or other substance which is active against retroviruses such as HIV. on the list of Essential Medicines that WHO says ought to be available in every country.
- Very importantly, WHO put out the first simplified HIV treatment [protocol](#) [10]A study plan on which all clinical trials are based. The plan is carefully designed to safeguard the health of the participants as well as answer specific research questions. A protocol describes what types of people may participate in the trial; the schedule of tests, procedures, medications, and dosages; and the length of the study. While in a clinical trial, participants following a protocol are seen regularly by the research staff to monitor their health and to determine the safety and effectiveness of their treatment that says, you know, you don't actually need to be able to do [viral load](#) [11]A measurement of the quantity of HIV RNA in the blood. Viral load blood test results are expressed as the number of copies (of HIV) per milliliter of blood plasma. or even CD4 tests to start people who are obviously dying on treatment, and in most cases you don't need 20 different drugs to chose from, either. Three or four basic drug combinations should be enough to meet the needs of most people in most places, certainly while programs start up.
- We also put out documents like this one that talks about how, in a place like Mozambique where you have 300 doctors for 1.5 million people with HIV, there's no way that treatment can be a doctor-driven process. You need to mobilize and train tens of thousands of nurses and community health workers and even people with HIV/AIDS to provide services. You know, once you've got people healthy again, let's give them a job working on an AIDS program, just as we do in Australia. It'll be a better program as a result. The idea of taking power from doctors and giving it to nurses and people with AIDS is still quite radical in some countries and especially for an organization like WHO that has always been run by doctors.
- We also had to use a lot of photographs like this – what I call the pornography of health – to make the case for treatment because in the end there is nothing like the Lazarus effect to persuade people that of course, it works. This is Joseph Jeune in Haiti and after 3 years he is still alive and well and he is the world's poster boy for antiretroviral treatment.
- Perhaps most importantly of all, we threw down a gauntlet to the international community by publishing a strategy saying what WHO would do to help reach the 3 million target by 2005, and some bright spark in the office branded the initiative "3 by 5". A team of 10-15 people developed this document over a period of three months that was probably the most chaotic and stressful experience of my life.

All of this work has been necessary because trying to get treatment urgently to millions of people in poor countries is actually not so easy. You need to get a lot of politicians on board. You need to get a lot of resources. You need to train a lot of people. In many cases you need to set up drugs distribution systems virtually from scratch. And you need to do this country, by country, by country. Many people didn't or wouldn't believe it could be done.

Providing treatment in developing countries is actually quite threatening to some very powerful interests, not least of all the brand-name pharmaceutical industry. A key component of WHO's approach has been to recommend fixed dose combinations – these are tablets that combine two nukes and a non-nuke in the one pill, and they're only made by generic manufacturers, principally in India. We had to spend many difficult months fending off the really sickening accusation from "think tanks" funded by big pharma in the US that by promoting fixed dose combinations, WHO was actually promoting "poor drugs for poor people". We've had to rebut the racist obscenity that, well, people in Africa don't wear watches so they won't take their pills on time, and this is all going to lead to an epidemic of drug resistance. We've had to work with the Treatment Action Campaign to counter genocidal arguments from denialists that it is antiretrovirals and not HIV that is killing up to 300,000 South Africans every year. On the very dark days it just seemed like these battles would never end.

We've had to bring a lot of people kicking and screaming along with us. Just persuading other UN agencies that they should be doing something about HIV, let alone treatment, has been more of a challenge than you might expect. I mean, this is what the UN system looks like, and WHO is tucked in here with the other specialized

agencies, and believe me, even though we're all supposed to be supporting the same 200 Member States, the UN is a veritable alphabet soup of different governing bodies and competing strategies and egos and agendas and rivalries and jealousies and turf battles. So we've had to bring UNAIDS and UNICEF and UNDP and UNCTAD and UNHCR and even at one truly absurd moment the UN Office of Out of Space Affairs on board, that has been a huge challenge.

Of course we've also had to contend with those who for all sorts of reasons – many of them quite legitimate – simply think that the World Hopeless Organization will just never be able to deliver on “3 by 5”, so it's really not even worth trying.

This is after all, an organization that is still clinging quite stubbornly to the traditions of the British and French bureaucrats who founded it in the '40s. It's a workplace that for some documents still requires the secretaries to have typewriters on their desks. Can you imagine? It's a place where most documents, from major reports to a requisition for toilet paper, are not circulated by email or logged into a database, but hand carried from one official to the next in a red leather binder. It's a place where everybody calls everybody else Dr This and Dr That whether you've been anywhere near a medical school or not. At WHO, people don't travel for work like ordinary human beings, they go “on mission”, presumably like the missionaries used to. You know, the pomposity can be extraordinary. It's no surprise to me at all that people wonder about the capacity of UN organizations to deliver anything they promise. It's hard to accept that despite its high ideals, the UN is flawed because it is a microcosm of a flawed world.

Perhaps the most difficult thing to accept has been that WHO never actually could deliver on “3 by 5” itself. Never. That's because WHO doesn't actually implement any treatment programs. We don't fly in with helicopters and tents and set up clinics. We don't pop a single pill in a single mouth. It's governments and public health systems that need to do that. All we can do is stick our neck out and make the moral and political case for treatment, develop protocols and guidelines, do technical support, and twist the arms of governments and donors. That means endless reams of documents and more endless meetings than you would think it is possible to sit through in one short lifetime. Sometimes you do wonder whether these interminable meetings and these mountains of guidelines are actually making the slightest bit of difference to a single living person.

A good illustration of the limits of WHO's capacity and how divorced it can be from reality in Geneva came the day I received a panic-stricken call from one of the secretaries in the office. There was apparently someone at reception. That someone being, well, someone who needed help. Someone who needed, well, treatment, to be precise. The secretary had tried calling lots of others people in the Department,, but no one, not one of these doctors actually had the time or knew exactly what to do with this person. You know, there was a god almighty panic: “Oh my god it's a real person”. Trotting out my skills from being a receptionist at the Positive Living Centre, in Melbourne, I went down and found a woman clutching the “3 by 5” strategy, this document, in her hand. She didn't read English too well but she clearly understood from somewhere that WHO was now promoting treatment for people with AIDS. With my rudimentary French I learned that her sister had just arrived from Cameroon and was in desperate need of treatment. Could I please help her sister? I had to explain to her that no, despite all the noise we had been making, I actually couldn't get treatment for her sister. We didn't actually have any treatment in the building. All I could do was refer her to the local [NGO](#) [12]Non-Government Organisation., and hope that they could help her. I felt helpless. I had to face the paradox that while I could talk and write about treatment for millions, WHO could not actually get drugs to a single person who came knocking at its door.

And to be honest, it is not a place that has historically been used to having people with an actual disease in its midst. To my knowledge I am the first openly-HIV positive person ever to work there, which is fairly astonishing for an organization with a workforce of about 10,000. When I arrived, it took me three months to discover, contrary to what I'd been told by senior managers really with no clue, that people with chronic conditions like HIV who had my type of contract have to wait six months before they became eligible for health insurance coverage. I'm immensely grateful to Jonathan Anderson in Melbourne for having shipped me my medicines for years now because otherwise I would have been paying \$2000 a month for drugs during that period.

In such an environment disclosing your status can be hard. I'll never forget a few months after I arrived sitting at a meeting in the Executive Board room, a very imposing room rather like the UN security council, with 30 or 40 people sitting at a big round table. During the course of introductions, to my considerable surprise, one very dignified woman lent into her microphone and said in a very measured voice: “I am a nurse. I work in the main hospital in Dakar. I am quite sure that I am the only person living with HIV in this very big and very impressive room”. I thought that she was very courageous to say that, and I just couldn't let it pass. When my turn came, I

said: "I'm Ian Grubb, I work in the HIV department and I just want my friend here from Senegal to know that she is not the only person with HIV in this room". I'll never forget turning off the mike, looking at my new WHO colleagues shifting uncomfortably in their seats and feeling myself turn absolutely scarlet with embarrassment.

Despite all the challenges, many of the planets do seem have to come into alignment. Throughout 2003 and 2004 it was as though the whole global herd of AIDS beasts had caught the smell of something in the breeze and slowly started to stir en masse. Under extreme moral pressure, companies began to offer much lower drug prices for the poorest countries. Generic manufacturing capacity cranked up. Kofi Annan's idea of a Global Fund for AIDS and other major diseases actually materialized. George Bush put 15 billion dollars on the table for AIDS and HIV treatment. And "3 by 5" began to capture the world's imagination. I'll never forget attending the last international PWA conference in Uganda – Suzanne Lau Gooley was there – when people began singing "Oh 3 by 5, we need the drugs". You know, when Africans start singing you know you're probably doing something right.. Treatment advocacy and preparedness have taken off in Africa and Asia and Latin America and even China. About 3,000 Thais are now [enrolling](#) [13]The act of signing up participants into a study. Generally this process involves evaluating a participant with respect to the eligibility criteria of the study and going through the informed consent process. in treatment programs every month. Since mid-2003, antiretroviral use in Cambodia has increased ten-fold, reaching more than 30% of people in need. Indonesia is beginning to expand treatment services for injection drug users, including methadone maintenance. We're seeing the potential expansion of treatment access in [PNG](#) [14]Papua New Guinea, one of the most challenging environments in the world. Malawi was initially planning to treat 2,000 people by the end of 2005; instead it is already treating 20,000. These are all major advances, not all due to WHO, by any means, but to the combined efforts of the international community.

In June of this year WHO reported that about a million people were receiving treatment. Not yet three million, but more than three times as many as were on treatment just two years before. It's a pretty good start. I really think we've reached another turning point, one where there's no going back on treatment in developing countries. The question now is how quickly we scale up, how quickly we use the hope and momentum that has been generated to keep moving forward.

I'm pleased to report that things are slowly changing for people with HIV in the UN system, too. In part as a result of pressure brought by people working on "3 by 5", every WHO staff member with a chronic condition now has health insurance from Day 1. And there is now a small UN Positive Staff Group, comprising people drawn from many agencies and countries, that aims to meet twice a year. In October, the group met with Kofi Annan and he offered us his very warm support. That is the sort of thing that really keeps us going .

The other thing that keeps me going is the view from my desk. It's rather like a metaphor for the work itself. Some days a thick pea soup hangs over the city and you cannot see a thing and it all feels very grey and grim and hopeless. On other days, when the sky is clear and you have a panoramic view of the French Alps, like this, that's my chair there, you feel that you are on top of the world and that anything is possible. All in all, it is really an immense privilege to be a part of it.

One of the happiest days of my professional life was in July of this year when the G8 leaders released their communiqué from Gleneagles. In it, they said that they would "work with WHO, UNAIDS and other international bodies to develop and implement a package for HIV prevention, treatment and care, with the aim of as close as possible to universal access to treatment for all those who need it by 2010."

Now, this is an extraordinary commitment by the richest countries in the world to get treatment not just to a few people, not just to three million, but to everybody who needs it, by the end of this decade. And while we may think that achieving universal access by 2010 is about as realistic as achieving world peace in the next five years, the fact is that a very serious public commitment has been made. I really believe that without "3 by 5", such a commitment would never have been possible. It's now up to us to keep the pressure on these governments, on the UN agencies and on ourselves, to deliver on this crazy commitment.

In closing, yes, the list of challenges is still huge, and I'll talk some more about that tomorrow. But I think these pictures show more eloquently than any words I could ever use, why we should have reason to hope. I think it's our responsibility as activists and as leaders in our communities to combine our legitimate intellectual pessimism about universal access with a public spiritual optimism that the global AIDS epidemic can in fact be stopped. If those of us surviving thanks to treatment don't have maintain hope, I don't know who else will.

Thank you very much.

- [2005 Conference](#)
- [conference presentation](#)
- [The global HIV epidemic](#)

**Links:**

- [1] <http://www.napwa.org.au/glossary/term/385>
- [2] <http://www.napwa.org.au/glossary/term/125>
- [3] <http://www.napwa.org.au/glossary/term/475>
- [4] <http://www.napwa.org.au/glossary/term/96>
- [5] <http://www.napwa.org.au/glossary/term/109>
- [6] <http://www.napwa.org.au/glossary/term/350>
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