

# Double Blind Inertia

## Diary of an AIDS Activist by George Smith

Dear Diary,

June 18th, 1988

Went to a meeting at the 519 community centre to hear Dr. Michael Sanders. He's a doctor from Washington, D.C. who was recently at the Stockholm conference on AIDS. He's also involved in the development of AIDS Community Research Initiatives (CRI) in the United States. CRI are a method of conducting community-based research undertaken by family physicians outside of large medical centres. They have worked well for devising new treatments for cancer patients and have made new research immediately available to people who are sick. The question is, will we be able to develop CRIs in Toronto (or in Canada) for AIDS? Is the Canadian medical profession innovative enough? What Michael Saunders had to say to those of us at

the 519 can be summarized in terms of two ideas. First, with state-of-the-art care, AIDS is no longer necessarily fatal. The problem is, however, where can we get state-of-the-art care? It is not yet available in Canada thanks to the inertia of the federal government and the Canadian Medical Association. And secondly, it is now important to begin to think of AIDS as HIV-illness that begins when a person is infected and not simply when she develops an opportunistic infection. Quite apart from whether or not AIDS is caused by HIV, what he was trying to emphasize is that early intervention is essential if the disease is to be managed. People survive longer if the disease is caught early. This raises the question of when, if ever, should high-risk individuals be tested?

In Toronto it is still possible to get at least a quasi-confidential HIV test. A number of people have thought that it would be possible to use a T4/T8 test ratio to do the same thing. Now, however, lab results are returned from local hospitals with the statement "this pattern is compatible with HIV infection" where the T4/T8 ratio is significantly less than 1.2. The well-being of high risk populations is coming increasingly to depend on the ability of the government to guarantee confidentiality.

July 5th, 1988

Went with a couple of other people from AIDS ACTION NOW! to visit the assistant deputy minister in the Ontario government concerned with AIDS and the Provincial AIDS Coordinator. The ADM wanted to know why it is that AIDS patients do more complaining about the treatment they receive than, say, people with cancer. This is an interesting question. The more I become immersed in the underworld of AIDS treatments, the more I wonder if everyone who is sick with a life-threatening disease has the same problems AIDS patients do.

July 13th, 1988

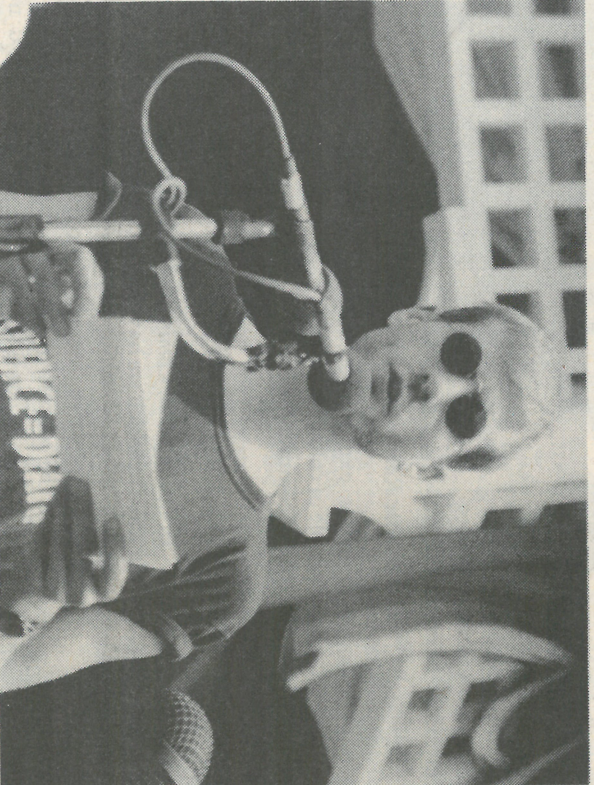
Jack, a member of AANI's media committee, has just been diagnosed as HIV-positive. As a result of this diagnosis he's decided to change doctors. His former doctor seems to be more interested in a professional

lifestyle than in dealing with patients with HIV illness. As a rule this gay doctor only spends 7 minutes per patient—the lowest limit OHIP can be billed for. It seems he wants the most from the medical insurance system. It seems even some gay doctors have difficulty putting the health of their patients first. I wonder if cancer patients have the same problem.

July 20th, 1988

Rumour has it that the Johnson report on double-blind placebo testing is about to be released. This is the report that was forced by the HIV-primary care physicians group, supported by AANI, on the ethics of double-blind placebo trials. It appears that Johnson is going to make two recommendations: first, that the placebo group be reduced from 150 to 100 and that the experimental

dapsone, is equally as effective as aerosolized pentamidine in controlling PCP, or for Toronto patients, that pentamidine is available in Buffalo? Patients getting their pentamidine from Buffalo do not take the one-chance-in-two risk of getting a placebo and possibly PCP. Lastly, how does an AIDS patient's doctor weigh the interests of his patient against the common good? Does a doctor enroll his patient in a drug because it is the best possible course of treatment for him, or does he enroll him in order to get the drug approved by the government, thereby making it available to everyone and more than likely increasing the profit margins of pharmaceutical firms? Does the AIDS patient in these circumstances become the sacrificial lamb? I wonder if cancer patients have the same problems?



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AANI's spokesperson Chuck Grochmal

group be increased to 200 from 150. Now a gay man with PCP has only a 1 in 3 chance of getting no drug when he is enrolled in the trials. Before it was 1 in 2. Secondly, Johnson has apparently said that the tertiary care doctors who are conducting the research should not enroll patients in these trials because of a conflict of interest. Patients should be enrolled by their family physician. Johnson has pointed out what has been known for a long time: doctors who stand to gain both monetarily and professionally by running the trials cannot be said to be acting solely in the interests of their patients when they enroll their patients in the test. This came as a shock to some researchers in Toronto's teaching hospitals who, over the years, have systematically enrolled their patients in treatment trials. It appears that Johnson's report has still not dealt with perhaps the two most central issues presented by this kind of double-blind placebo test. First, the issue of catastrophic rights: Do patients with life-threatening illnesses have an automatic right to treatments they and their physician believe to be beneficial, especially if these treatments have been shown to be effective? This is clearly the case with aerosolized pentamidine. And secondly, in signing up patients for trials, what counts as informed consent? In the case of PCP, for example, do doctors have to tell a patient that the anti-leprosy drug,

July 25th, 1988

Jack went to the AIDS Mastery session this weekend. He really enjoyed it and thought he got a lot out of it. He is now bent on staying healthy. His thrush and hairy leukoplakia are coming under control and he has started on a regime of zinc and monolaurin. Monolaurin is an antiviral agent that was written up in *AIDS Treatment News* last year. Zinc is thought to be an immune booster.

July 27th, 1988

It seems as though there might be a drug trial for dextran sulfate. The company in Scarborough that produces the drug has approached the federal government. Again, a drug that has shown to be effective will be denied to PLWAs until the Canadian government conducts its own tests. The manufacturer expects the trials to begin in September, but word has it that the government committee that oversees funding these kinds of trials only meets twice a year. So I guess PLWAs and HIV-positive individuals who can afford it will have to order their dextran sulfate from the Bahamas. \$400 US for 1,000 capsules. Poorer individuals will just have to wait till the government gets round to funding these trials. And even then, there is only a 1-in-2 chance that they will actually get the drug. The dextran sulfate trial will also be double-blind.

## Queer Camping

Thinking about going camping? If so, you may have heard about a lesbian and gay campground an hour's drive from Toronto called *The Cedars*. For those of us who enjoy camping, but not in the closet, this should be great news. It isn't. *The Cedars* is located on what is essentially lightly wooded, uncultivated farmland and horse pasture, within hearing distance of the Flamborough Speedway (a racing car track). There is no water for swimming, save a small pond, which was unfortunately quite muddy looking because of the lack of rain. The proprietors also provide "barn dances" on weekends, which is great for those of us who want to get out of Toronto without missing a weekend of the bar scene. When we asked a camp worker what people do for recreation, he replied, "Drink beer." If you like to "party till you puke," and can go without sleep for an entire weekend, *The Cedars* is the place for you.

Despite the lack of facilities, clearly a lot of people think that the place is just great, because it does after all provide a much needed space, whether you need a weekend's escape from a city, or an escape from a closeted existence in small town Ontario. The other women camping in our area were very friendly, stopping by for a visit or waving as they passed in their cars. Here we were in a much-needed space, camping out with our sisters and gay brothers, and not a nuclear family in site. Here was a place where we didn't have to pretend we were just "good friends." This, we thought, would certainly compensate for the campground's shortcomings. But when people have nothing to do but drink all day and night (and this was obviously the most popular pastime), there are bound to be problems, and from the stories we heard from other campers, there was no shortage of them.

Ours began at about 1:30 in the morning, as we were drifting off to sleep. The campground was quite noisy (it stayed that way until the sun rose) but the hooting and hollering and music was far enough away from our site that we could tolerate the noise level. However, the three young men at the campsite behind us (what were they doing in an area that was otherwise full of women?) returned from the disco barn dance and began to absolutely blast their music, so that our neighbors, who were even further away from them than we were, began to yell at them to turn it off. One of us reluctantly left a finally warm sleeping bag and asked them to turn it off as people were trying to sleep, a quite unreasonable request indeed. The other followed a couple of minutes later, when it became clear from the shouting that things were not going well. The long and short of it is that we were assaulted by these drunks. One of us was thrown to the ground by one of the young men and held down by the throat. The other of us grabbed him by the hair to stop him and was seized by another guy, punched in the side of her head, and thrown to the ground. A third fellow crouched over the one of us who was pinned to the ground by her throat, leaving her to wonder what the next move was going to be.

Fortunately, a neighboring camper appeared and intervened. Promising assault charges, we went to get the police, but on our way encountered the owner of the camp who insisted on checking things out for himself. He, it turned out, was no help, alleging that there were two sides to a story, and that we should not have gone on their campsite and told them to turn the music off in the first place (despite the fact that the rules stated that there was to be "no loud partying after 11pm"). When we asserted that an assault was an assault, he said that we had an attitude problem. Unfortunately, the woman who was camping beside the young rowdies and had intervened earlier was no help either; she, for reasons known only to her, apparently said that one of us had "thrown the first punch." We do know that she and her friends had been socializing with these fellows earlier in the evening. Perhaps a shared beer is enough to cement the staunchest, if most misguided, of loyalties.

Given that it was 2:30am by then, we were quite shaken up, the road to the nearest phone was full of drunks, and the police would take at least an hour to arrive, we decided to leave contacting them until the next day. We weren't wild about inviting them into the only gay and lesbian campground around, since cops have not exactly been our staunchest allies, but we were certainly not going to sanction male violence in order to "protect" the place. When their yellow squad car pulled in to the campground, it became clear who a number of the other campers thought the real troublemakers were. Better to dismiss male violence towards women than to bring in the boys in blue. We were referred to as "finks" and our pictures were even taken from the doorway of the proprietor's house, probably to keep on file in case we should ever attempt to return.

*The Cedars* might bill itself as a gay and lesbian campground, but it seemed more like the standard seedy bar scenario run by a straight, sexist entrepreneur. However, our concerns lie with our "sisters and brothers" who will defend "the bar," whether it is in the city or out in the "Back 40," even in the face of such a blatant eruption of male violence and misogyny. We expect such misguided loyalties from the REAL Women of the world; we never expected it from other lesbian women. We had walked in solidarity with gay men the weekend before during the Pride Day march, as part of what is as yet a very young political alliance. Our experience confirms the fragility of that alliance. What we have experienced typifies the male behaviour many of us have committed our political lives to fighting against. Whatever *The Cedars* may mean to gay men and unpolicitized lesbian women, we certainly do not consider it a safe or welcome place for women, period.

Debi Brock and Jennifer Stephen