

AAHP  
**AIDS Activist History Project**

**George W. Smith Articles**

*Prepared by members of the AIDS Activist History Project, this document includes transcriptions of various articles written by George W. Smith. Please note, that some of the articles and transcriptions are incomplete.*

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### **Talking Politics: Vancouver PWA Coalition Shows the Way**

By George Smith

Nov. / Dec. 1987

In the past month in Toronto the biannual review, Fruit Cocktail, played to full houses and the Gay Community Dance Committee's Halloween Dance has been sold. In the United States our brothers and sisters, six hundred thousand strong, have marched on Washington demanding civil rights and better healthcare for people with AIDS. And in Vancouver, the PWA Coalition began a pilot research study on the effectiveness of Egg Lecithin (AL-721) in limiting the ability of the AIDS virus to attack T-cells.

This, of course, is not the first time the Vancouver PWA Coalition has taken the initiative in the treatment of people with AIDS. Last year, it marshalled its membership to force the federal government to begin trials with AZT – which, according to recent reports in the *Globe and Mail*, is still the only anti-AIDS drug approved by the federal government.

In its September newsletter the Coalition announced that it was forced to take the matter of AL-721 into its own hands because of a lack of support, both federally and provincially, for AIDS research. Not only is there a lack of funding in basic research, there is little or no interest in new drug therapies being developed elsewhere, including AL-721. A list of new drugs not yet tested and approved in Canada includes, among others: dextran sulphate, amipligen, DNCB, Foscarnet, Imeg-1, Imuthiol, isoprinosine and ribavirin.

The Federal AIDS Centre, the national agency responsible for co-ordinating government policy on AIDS, has virtually no presence in the country and provides no leadership in mounting a concerted effort directed at treating and finding a cure for the disease. In a recent television clip, Alastair Clayton, its director, eschewed a pro-active stance in the present AIDS crisis, suggesting instead that his main concern was balancing his budget. Not surprisingly, the \$1.5 million dollar grant the federal government has given to the University of Toronto AIDS study is small potatoes when it comes to funding major medical research.

In all of this, the government is supported by the Canadian medical establishment that attempts to attribute its overly cautious approach to drug testing and approval to its greater "professional" concern for patients, or its "superior" scientific ability. Wrapped in this kind of smugness, medical personnel in the federal government are prepared to await the results of treatment testing and research in other places before approving new drugs. Like a cat chasing its tail, the "success" of this strategy – the few drugs that are approved are usually useful – in turn, is used to support their view of their own "superior" professionalism and scientific expertise. What really stands behind this face-saving device is the failure of governments in Canada to provide funds to establish laboratories that can develop and test drugs. While the Canadian medical establishment tries to put on a good face, the problem is still one of nothing ventured, nothing gained. If every country took this approach to the treatment of AIDS, we would wait forever for a cure.

The wait-and-see approach Ottawa is taking in approving drugs, particularly because of its dependence on the results of the U.S. testing, leaves Canadian PWAs victims, by default, of Federal Drug Administration (FDA) policies south of the border. Recently, the National Gay Rights Advocates (NGRA) has alleged in a law suit that the FDA has accelerated testing and approval only for drugs which have been developed or sponsored by its own National Institutes of Health (NIH). NGRA further alleges that there is collusion

between the NIH and pharmaceutical firms such as Burroughs Wellcome and Hoffman-LaRoche in processing drug approvals. Firms that have their drug patents approved first by the U.S. government stand to make big bucks, as the cost of AZT and the rising share prices of Burroughs Wellcome have shown.

In the United States, California, with one of the largest numbers of AIDS cases, is considering by-passing the FDA, and its connection to major drug interests, to develop its own facilities for testing and approving drug therapies. As reported in the *New Scientist*, California says that the FDA is too slow in responding to the AIDS emergency. Because of Ottawa's approval policy Canadian PWAs are even further down this drug pipeline. In the past few months, Fusidin acid has been used to treat AIDS in Denmark and England with surprisingly good results. The question is, How long are we prepared to wait until drugs like this are capable of being tested and approved quickly here in Canada?

One of the people I live with has been going daily to the Toronto General Hospital to see a friend who had been hospitalized with his first bout of PCP. He was being treated with the drug Septra with serious side-effects that were treated in turn by another drug with again serious side-effects. The treatment, needless to say, was extremely hard on him. In San Francisco doctors have developed an aerosol form of Pentamidine which has proven to be an effective drug against PCP. The aerosol allows tiny droplets of the drug to go deep inside the lungs without serious side-effects. Used once every two weeks, Pentamidine in aerosol form even acts as a preventative to further PCP infections. Aerosol—Pentamidine, however, is not approved in Canada for the treatment of PCP.

*George Smith is a former chairperson of the Right to Privacy Committee and longtime gay activist.*

**Smith, G. (1988, May). "Talking Politics by George Smith – Socreds Make Strange Bedfellows." Rites. Vol. 5, No. 1. P. 8**

### **Talking Politics by George Smith – Socreds Make Strange Bedfellows**

Stan Persky, a well-known writer on the west coast, recently published an article in This Magazine—entitled “AIDS and the State.” In it he defended the “improvements” the British Columbia Civil Liberties Association made to the B.C. government’s quarantine legislation affection people with AIDS>

The legislation, as amended, gives medical authorities the power to place in quarantine anyone who “is likely to willfully or carelessly expose others to the disease.” In the struggle over the bill, the BCCLA and the Social Credit government were pitted against a grass-roots, left-leaning organization, the Coalition for Responsible Health Legislation, composed of lesbian and gay activists, and people organizing around the rights of prostitutes.

All public health authorities across the country operate with some form or other of quarantine legislation. B.C., however, is the only jurisdiction in Canada to have enacted a new legislation with HIV-positive individuals in mind. It is also the only jurisdiction in Canada to withdraw government payment of AZT costs for PWAs. And if this were not enough, it is presently engaged in a religiously-inspired, \$20 million, right-wing, government- sponsored, anti-abortion campaign.

While Stan Persky defends the BCCLA’s actions as a clever political strategy to amend the bill, and contrasts it with what he views as the ineffectual populist tactics employed by the Coalition, the effect of the legislation will ultimately reside in how it will be employed, the “motives” of the present government notwithstanding. The B.C. government, having disbanded its human rights commission some years ago, is not well known for its defense of civil liberties.

Stan, as it turns out, is a member of the B.C. Civil Liberties Association’s board of directors, and holds a similar position with AIDS Vancouver. One thing that he does not mention in the article is the resignation of Bob Tivey, the former executive director of AIDS Vancouver and a long-time AIDS activist, over the failure of the organization to oppose the legislation.

One of the most interesting features of the article is how it looks at the world of AIDS through the eyes of heterosexual professionals. It is true that Stan does not hide the fact that he is homosexual—a homosexual who has been tested and is HIV- negative. There is a difference, however, between coming out to readers and taking up political issues from the standpoint of lesbians and gay men. Think of all the heterosexuals who flock to drag queen shows to be titillated by the foibles and stereotypes of a heterosexually gendered world. Drag queens are openly homosexual without posing any threat to the hegemony of heterosexism.

How does Stan buy into this kind of thing? Well, first, he has a heterosexual view of AIDS as a disease caused by reckless gay men, bent on an immoral life style, who pose a serious threat to public health. To set this kind of frame in place, he borrows the story of Patient Zero from Randy Shilt’s book, *And the Band Played On...* Patient Zero is a French Canadian flight attendant who allegedly is the “foreigner” who brought AIDS to the US. OF course, what we know now is that people have been dying from HIV infection in the United States since the late sixties. In fact, Patient Zero could have gotten the disease in the States.

This story is a piece of xenophobia typical of accounts of sexually transmitted diseases. Remember that at the time of the great syphilis epidemics in 16<sup>th</sup> century Europe, the English called it a French disease and vice-versa. In a Canadian context, however, this kind of story is not merely xenophobic, it is racist.

The heterosexual framework is further developed by referring to AIDS as a “plague,” which triggers in the mind of most people “gay plague,” and by his use of staunch anti-sex rhetoric. Stan’s anti-sex position begins with his attack on the gay left and even includes a condemnation of “safer sex”—one practice that, in recent years, has been very effective in keeping the rate of HIV infection low in places like San Francisco.

In heterosexual land there are two kind of gays: good gays, and bad gays. “Good gays” live discretely in couples and, of course, are HIV-negative. They also support the political establishment, including the authority vested in cadres of professionals whose job it is to manage other people’s lives. The “bad gays” are willfully promiscuous activists who constantly refuse to relinquish their lives to the authorities no matter whether these are professionals in the criminal justice system, the media, or the medical establishment. Heterosexuals perceive these people to be a threat to public order. Consequently, activists are either to be suppressed by the police, for example, or, in these days, left to die of AIDS.

Stan’s attack on gay activists is also a media frame he lifts from Randy Shilts’ book. He begins by attacking *The Body Politic’s* editorial line. In constructing his account, he accuses TBP of not taking AIDS seriously “when the plague broke out in 1981.” If the truth be told, in 1981 nobody knew anything had broken out. It was not until 1984, in fact, that the HIV virus was identified as the cause of AIDS. Until then, knowledge of the route of transmission was speculative at best.

What was clear, nevertheless, was that the disease was striking down gay men. This was enough for the radical right and Christian fundamentalists to begin what was to become a virulent homophobic campaign against lesbians and gay men. What should have been a medical issue, became a struggle around the right of fundamentalists to impose their lifestyle on others. In fact, the first program the CBC’s *The Journal* aired on AIDS was a debate between Jerry Falwell and MCC’s Troy Perry on the theology of the disease.

It became necessary, in this environment, for gay activists to take the offensive against the right wing. Not only to try to prevent the passage of draconian and offensive legislation, such as BC’s quarantine law, but also to help people stricken with AIDS cope. It is one thing to come down with a fatal disease, it is another to believe that you are morally responsible for your own illness. This, however, was the message of the church and of the media.

For his final twist of the knife in the back of the gay left, Stan accuses gay activists of playing no role in the development of organizations such as AIDS Vancouver. Ironically, it was Bill Lewis, a biomedical researcher at the University of Toronto and gay activist, who wrote the first article in *TBP* on the politics of AIDS (*TBP*, Nov. 1982), and who later became one of the founders of the AIDS Committee in Toronto. Bill’s article was an effort to sort out medical fact from media hype. It was not an attempt to promote “absolute sexual freedom,” as Stan suggests, but an attempt to get people to examine the scientific basis of the disease.

Of course, during this time *TBP* was waging its own struggle against the Ontario provincial government around the issue of censorship, involving a long drawn out series of court cases. But again, a fight against censorship should not be construed as a demand for “absolute sexual freedom.” The fact that Stan, a homosexual man who sits on the board of civil liberties association, gets into this kind of muddle serves only to show where he is coming from.

It should be said, of course, that gay activists have had a hard time working within AIDS organizations because these groups do not have an activist orientation. This is, in part, because most of them are organized on a professional basis. They invariably relate to HIV-positive people as clients, with all the lack of autonomy and disempowerment power relations of this sort entail. Moreover, AIDS organizations, on the whole, have been content with providing only education for the public and hand holding for PWAs until they die.

Stan, himself, is an example of how the board of AIDS Vancouver is tied to the board of the BC Civil Liberties Association. Again, there is the authority vested in cadres of professionals. Similar kinds of professional relations exist between AIDS groups and health care professionals and assorted volunteers who bring their professional expertise to the work of caring for PWAs. These people act out of the purest of motives, but they only know how to care for people professionally. The PWA is always cast in the role of the “other.”

These professional relations are further entrenched by government funding of AIDS groups. Criticism of government policy is often muted by professional practice. No one is prepared to excoriate either provincial or federal governments for failing to deal with AIDS as something other than a fatal disease. It was left to the Vancouver PWA coalition, for example, to force the federal government to begin testing AZT. And again it was the Coalition that began the first community research initiative to test AL-721, a purported non-toxic, anti-viral drug.

In North America and parts of Europe a new breed of AIDS activist organizations have begun to fight for the rights of the living to proper medical care: both in terms of the development and testing of anti-AIDS drugs, and of the provision of proper standards of care in hospital facilities. Even today, for example, there are no standard hospital diagnostic and treatment protocols for dealing with PWAs.

Interestingly enough, it was these kinds of medical issues that were taken up in the *TBP*'s first editorial on AIDS (*TBP*, May 1983). The editorial asked, “Why have provincial, state and federal governments not acted as quickly as possible to fund primary research of AIDS? Why have ministers of health been utterly silent about the disease that has already killed more people than swine flu, toxic shock and Legionnaire’s disease combined?” It went on, “The medical establishment encourages secrecy, fierce competition for funding and individuals career-building over speedy solutions to health problems...Scientific information is being held back. Could that information be helping save lives right now?”

Unfortunately, these questions are as relevant today as they were five years ago. These, and questions like them, however, are providing the agenda for the new wave of gay/AIDS activists. Besides the Vancouver PWA coalition, there is also AIDS ACTION NOW! In Toronto and various ACT UP chapters across the United States. The politics of these organizations are intended to breathe life into people with AIDS.

--- George Smith

George Smith is a member of AIDS Action Now! And the Right to Privacy Committee.

**Smith, G. (1988, June). "Talking Politics by George Smith --- Diary of an AIDS Activist." *Rites*. Vol. 5, No. 2. p. 7, 19.**

### **Talking Politics by George Smith --- Diary of an AIDS Activist**

Dear Diary:

April 22<sup>nd</sup>, 1988

A chance encounter with a friend on Yonge Street today. He looked thinner than the last time I bumped into him. He told me they had just diagnosed lymphoma of the liver. He's going to start going in for treatments next week. When he told me about the diagnosis, I really didn't know what to say. What can anyone say? He's dying of AIDS.

April 25<sup>th</sup>, 1988

Called Gary today to see if he could do some work for AIDS ACTION NOW!. We need a button and an ad designed for Lesbian and Gay Pride Day. He's just gotten out of the hospital with his second bout of PCP. He seems to be doing fine, but he's still not up to working on the design. He told me that when he went into the hospital a couple weeks ago, his doctor had left instructions that he not put on sepra—the "drug of choice" for treating PCP. He's allergic to it. Of course, the first thing the doctor at the hospital did was to put him on sepra. Power games in the medical establishment.

April 26<sup>th</sup>, 1988

Another meeting of AIDS ACTION NOW!. Plans afoot to go to Ottawa to protest the inaction of the Federal AIDS Centre on the development of new treatments for AIDS Infections. Hope to fry a few big fish, like Jake Epp, the minister responsible for AIDS policy in the federal government. He calls himself a Christian, but I don't think he'll ever come to care about the survival of PLWAs. It's enough to give Christians a bad name.

There is a meeting of the Canadian AIDS Society the middle of next month. It will provide AAN! With an opportunity for networking. How many organization will be able to get to take up the "Politics of Treatment?" (I like this concept. I think I'll use it in the future to talk about the lack of proper treatment in terms of both the availability of new drugs and proper hospital care for PLWAs). Unfortunately, it seems very hard for people to see AIDS as anything but a fatal disease. When will AIDS organizations begin to focus their work on strategies for survival?

April 29<sup>th</sup>, 1988

Met Jeff today. Like most PLWAs he's very critical of the way he's treated in the hospital. There seem to be real problems with hospital-based doctors, the so-called "tertiary-care physicians." It's like they are more interested in research than in caring for their patients. Some, for example, have argued strongly for double-blind placebo drug testing on PLWAs. THIS might improve their publication record, and help their careers. It would also improve the profits of multinational pharmaceutical firms that require this kind of testing to market their products. But there is not much in it for PLWAs who end up being treated like guinea pigs. Even Ronnie Reagan's AIDS Commission thinks this practice is unethical.

There are a number of hospital-based research programs in Toronto, but we don't yet have an AIDS clinic in the city devoted to the care of PLWAs. In fact, except for a small band of general practitioners, or so-called "primary-care physicians," doctors in the city have been very narrowly defining their responsibilities for their patients when it comes to AIDS related infections. Most of them are prepared to make do with the few treatments that are available. How can they justify this in terms of their professional ethics?



May 4<sup>th</sup>, 1988

AAN! Is hosting a conference on care facilities for PLWAs. The only major group that have yet to register are tertiary-care physicians from the large teaching hospitals in the city. They don't seem much interested in coordinating care for people living with AIDS.

May 5<sup>th</sup>, 1988

Last week the children's hospital in Halifax went to court to try to snatch away from his parents a young boy suffering from leukemia. His parents, devout Christians, had taken him home to die after his first chemotherapy treatment. The hospital felt morally obliged to try to prevent this boy from dying. Why don't hospitals feel the same way [Continued on p. 19] about PLWAs? Everyone in the medical establishment connected with AIDS knows, for example, that the Federal Centre for AIDS is ineffectual as far as developing new treatments for AIDS-related infections. Perhaps we can take the federal Minister of Health to court to force him to take up the survival of PLWAs more seriously.

The physicians who see this most clearly, the doctors responsible for testing drugs, are the tertiary-care physicians. They do nothing. Their ethical obligations in treating their patients seem restricted to the use of standard, but very toxic drugs. They have failed, for example, to lobby publicly for access to promising, often less toxic drugs, being tested in the US and elsewhere. And although people are dying every week of AIDS, they have not yet asked for a public investigation of the operations of the Federal Centre for AIDS, nor for the resignation of Jake Epp, the federal Ministry of Health and Welfare. Perhaps this is too much to ask of the medical establishment.

May 6<sup>th</sup>, 1988

Sent a copy of "AIDS Treatment News" to John this week. It had an article on people surviving with AIDS. He's had KS for about four years now, but still goes to work every day. Lately he's been on chemotherapy which is helping. He's coming to think of himself as a "survivor." There is increasing evidence from the US that some people are living a lot longer with AIDS than expected. The Canadian medical establishment doesn't appear to be very interested in these developments, however. AIDS doesn't seem to be a disease doctors are interested in getting out and fighting.

May 7<sup>th</sup>, 1988

A friend from Ottawa called today. I had asked him to investigate the Federal Centre for AIDS. As it turns out, FCA is more or less a front organization for the Tory government. It seems as though the Centre has no money. What's even more important is that the 43 or so people working there have been seconded from other branches of the Department of Health and Welfare. The Centre does not have its own staff and appears to be operating as a stop-gap, policy front—a smoke screen hiding government inaction. My friend also told me that the AIDS Committee of Ottawa cannot find office space. As soon as the landlord know AIDS is involved, it is impossible to get a lease.

May 8 1988

Went to hear Margaret Duckett Friday night. She was sponsored by the Medical Reform Group of Ontario. She's visiting professor at McGill University's Centre for Medicine, Ethics and Law and a special advisor or AIDS to the Australian Government. Her talk, in many ways, was politically correct—no mandatory test, no quarantine, etc. But she seemed only to be interested in public health problems. Apart from criticizing the multinational pharmaceutical firms, she had little to say about the "politics of treatment." She did not appear

to take seriously, for example, the rights of PLWAs to treatment they and their physicians think might be useful. In addition, the fact that there are no hospital diagnostic and treatment protocols for dealing with AIDS as there are for other diseases, didn't seem to raise any ethical issues for her.

May 10<sup>th</sup>, 1988

Saw last night some of the preliminary results of AAN!s questionnaire for PLWAs on the kind of care they are receiving at Toronto hospitals. The results, so far, indicate serious problems. Will have to wait till all the results are in, however. AAN!s Pentamidine Project that gives PLWAs access to aerosolized pentamidine now has 20 participants. We're going to have to redouble our efforts at giving this project visibility in the community. There are still people who might benefit, but don't know about it.

--- **George Smith**

**Smith, G. (1988, July). Talking Politics by George Smith – Diary of an AIDS Activist. Rites. Volume 5, No. 3. P. 11. Special Lesbian and Gay Pride Day Issue.**

### **Talking Politics by George Smith – Diary of an AIDS Activist**

Dear Diary,

May 15<sup>th</sup>, 1988

Went to the Canadian AIDS Society (CAS) Conference with Gary to talk to people interested in AIDS activism. The first thing we did was to ask them to describe the political situation, as they saw it, for People Living With AIDS (PLWAs) in various parts of the country. The differences were quite amazing. People in Vancouver, for example, are constantly having to do battle with the Bill “wacky” Vander Zam, the Premier of B.C. On the other hand, groups in smaller cities have as much as they can do to help their own PLWAs cope day-to-day.

We agreed in this workshop to do two things: to organize a phone-in on May 24<sup>th</sup> to Members of Parliament to complain about government AIDS inaction; and to set up a national network of people interested in AIDS activism. It was good to meet other people in the country who are interested in pushing the government and the medical establishment to do more for PLWAs.

May 16<sup>th</sup>, 1988

Missed the Die-In at the Sheraton Centre this morning. It took place at the beginning of the Canadian Public Health Association Conference (the CAS and CPHA Conferences were run back-to-back). I was busy running around getting the media releases printed and packaged. It seems, from all reports, that the Die-In was quite a success. It certainly caught the media’s attention. AIDS ACTION NOW!’s media conference, later in the day, was not all that well attended, however. I hope that our message about the importance of experimental treatments is getting out. People’s lives depend on it.

The deputy minister of health, Maureen Law, addressed the CPHA conference. Members of AIDS ACTION NOW!’ public action committee stood and unfurled the banner “EPP=DEATH”. This was the message of the day. Later in the afternoon there was a rally and march from the Sheraton Centre to the offices of the Tory party, where AAN! demands were pasted to the door of the building. The march then went back to Nathan Phillips square in front of Toronto city hall where Epp, the federal minister of health, was burned in effigy.

This action was not without its moments of tension. The march left the Sheraton Centre taking the Queen Street sidewalk. But, a block later, when we turned onto Richmond Street, the march was so large that the head marshal decided to take the south half of the street, blocking traffic. The police moved in with horses and reinforcements. All we needed was for the police to attack the march. For a moment I thought this might happen. Many of our marshals were new to their job. As a result, the situation was not always well at hand.

As we approached city hall, the police moved to bar us from Nathan Phillips Square in front of city hall because we did not have a permit. Fortunately, Metro Councillor, Jack Layton was marching with us and told the police we were his guests. So they let us in—but not before councillor Layton had to produce his ID, and then we burned Jake Epp real good.

On the evening news, an incredible thing happened. The events over the past two days, organized by AAN!, were reported as the work of the entire conference. Of course, a large number of individuals attending the conference had joined the march. And earlier in the day the Canadian AIDS Society had held a news conference to attack the federal government. But it was also clear that people from across the country felt very deeply about the government’s lack of leadership on AIDS treatments. It was really great that AAN!’s

activist politics had struck such a resounding chord, and were able to focus, in a public way, the real concerns of PLWAs and AIDS workers at both conferences. It is when these kinds of things happen that you know that you've got your politics right.

May 22<sup>nd</sup>, 1988

Spent most of the afternoon with AAN's media committee getting the press releases ready for the trip to Ottawa. The main news conference will be held in the National Press Theatre across from Parliament Hill. We've prepared bilingual media releases to make our trip to Ottawa a "federal" event.

May 24<sup>th</sup>, 1988

Bernie, a member of the media committee, and I left on the train for Ottawa after a hectic day of getting the press releases ready and alerting the Ottawa press corps of our imminent arrival. Bernie spent most of the time on the train translating the last of the press releases. When we got to Ottawa, I learned that Ross, a PLWA who works on the media committee, and who we had arranged to fly in, was sick in hospital with his second bout of PCP.

May 25<sup>th</sup>, 1988

Today was a madhouse! It started with a demonstration in front of the Federal Centre for AIDS. From the FCA, we marched with our banners to the National Press Theatre where we were joined by Svend Robinson and Sheilla Capps for a press conference. While the press conference was going on, a bunch of people from the public action committee of AAN! set up some tables on Parliament Hill. Immediately after the press conference we went to the hill to demonstrate the use of three anti-AIDS drugs that are either not available in Canada, or in the case of Pentamidine, not available in aerosolized form. The other three substances were dextran sulphate, AL-721 and naltrexone. During the press conference, the media focused in on the conflict of interest between Epp's religious beliefs and his responsibilities as Minister of Health and Welfare. Like Vander Zalm in B.C., it appears that he is trying to use his political position to foist his religious views on the country.

While we were at the Federal Centre for AIDS, we learned that Epp wanted to meet with representatives from AAN!. We turned down his request because the meeting was a last minute thing, and had not been properly planned. Also, we saw the proposal as merely a damage-control exercise on the part of the federal government. We didn't think much would come of it, as a result. The same could be said for the head of the Federal Centre for AIDS joining our march down Elgin Street from FCA to the press conference. The man who has done more than most to obstruct treatment for PLWAs tried to pretend that he was for AIDS ACTION NOW! What hypocrisy!

May 30<sup>th</sup>, 1988

Jake Epp was in Toronto today to meet with the AIDS Committee of Toronto, and the PWA Foundation. Again, AAN! declined to participate in this meeting because it had the smell of closeted, back-room politics. Nevertheless, the people who did go said that Epp and Barabara McDougall, who arranged the meeting, were listening. In particular, it appeared that both of them learned for the first time that AIDS is not necessarily a fatal disease. Only time will tell, however, if this will do anything to make more experimental drugs available to HIV-positive people.

June 2<sup>nd</sup>, 1988

Representatives of ACT, the PWA Foundation and AAN! Met with Elinor Kaplan, Ontario's Minister of health, today. They were originally asked to brief the minister for her trip to Stockholm AIDS conference. During the meeting the minister was very defensive and taciturn. Most of the talking was done by the government civil servant responsible for AIDS who appears to be very homophobic. From a public relations point of view the meeting was a disaster for Kaplan. It is really strange: the meeting with Epp, who is seen in quite a negative light, was much better than the meeting with Kaplan, a minister in a Liberal government which people would ordinarily expect to assume a more progressive posture.

June 3<sup>rd</sup>, 1988

Ross got out of the hospital today in time for Vito Russo's Celluloid Closet. He's still not able to get aerosolized pentamidine. His doctor, however, has arranged for him to use IV pentamidine on an out-patient basis. The stuff is pretty toxic. In Toronto hospitals these days there is no rhyme nor reason to the kinds of treatments PLWAs are receiving.

June 8<sup>th</sup>, 1988

Today Jake Epp announced \$129 million for AIDS. Unfortunately, the bulk of it will be spent on more educational programs that don't work; not because people can't be educated, but because the programs, which don't deal frankly with AIDS, fail to communicate. Only \$38 million is slated for research and it is yet to be seen how much of this will be for experimental treatment research. When will the government see that treatment research is the No. 1 issue?

Smith, G.W. (n.d.). "Talking politics – Police shape politics of AIDS. *Rites* (p. 4)

### **Talking politics – Police shape politics of AIDS**

By George Smith

It looks as though the police in Toronto will continue to shape the politics of AIDS in the city for some time to come without much resistance from the community. Recent police initiatives, for example, have set harsh standards for the treatment of PWAs in the mind of the public. They also appear to be contributing to the spread of the disease by hampering efforts to promote safer sex.

The latest event occurred last week when Toronto newspapers reported the teargassing of a PWA apparently suffering from AIDS dementia. According to the papers a doctor and the police had a warrant for the man's committal under the Mental Health Act. However, he refused to surrender. In response, the police sent in the Emergency Task Force which lobbed two tear gas canisters into his home. He was then captured, strapped to a stretcher and taken to the Toronto General.

The way this case was handled it would seem that neither the police nor the medical personnel on hand were adequately trained in handling AIDS cases. Moreover, the reporting of this event in the city's newspapers carried two important political messages: 1) AIDS is a highly contagious disease. And 2) the only way to deal with erratic and volatile PWAs suffering from AIDS dementia is to tear gas them. As a result, the police have produced more AIDS hysteria and at the same time have created a new stereotype of people with AIDS as diseased, violent and dangerous. Toronto's gay community has yet to insist that this kind of treatment on the part of the police is unacceptable.

This event follows three months after the police threatened steambaths for giving out condoms to customers as they entered, with charges under the bawdy house law. Apparently, giving out condoms, these days, is tantamount to sex in public. Complaints by local politicians got the police to renege and to permit condoms to be given to patrons upon leaving the baths. This, of course, is like closing the barn door after the horses are gone. The result has been that in the two bathhouses that have been giving out condoms, they are now simply left out in a bowl. Community efforts to promote safer sex have, consequently, been seriously undermined by the Toronto police, well known for their homophobia. [this article continues]

Smith, G.W. (1998, September). "Diary of an AIDS Activist by George Smith – Double Blind Inertia." Rites, p. 9

### **Diary of an AIDS Activist by George Smith – Double Blind Inertia**

Dear Diary,

June 18<sup>th</sup>, 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 professional 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 necessary 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 5<sup>th</sup>, 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 becoming immersed in the underworld of AIDS treatments, the more I wonder if everyone who is sick with a life-threatening diseases has the same problems AIDS patients do.

July 13<sup>th</sup>, 1988

Jack, a member of AAN! 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 20<sup>th</sup>, 1988

Rumour has it that the Johnson report on the 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 AAN!, 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 group be increased to 200 from 150. Now a gay man with PCP has only a 1 in 3 change 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 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 trails cannot be said to be acting solely in the interests of their patients when they enrol their patients in the test. This came as a shock to some researchers in Toronto's teaching hospitals who, over the years, have sympathetically 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 trails, what counts as informed consent? In the case of PCP, for example, do doctors have to tell a patient that the anti-leprosy drug, dapson, 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 who do not take the one-change-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?

July 25<sup>th</sup>, 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 anti-viral agent that was written up in *AIDS Treatment News* last year. Zinc is thought to be an immune booster.

July 27<sup>th</sup>, 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.



Smith, G. W. (1983, January/February). "MEDIA FRAMES: How accounts are produced and read." *FUSE*. p. 279 to unknown.

## **MEDIA FRAMES: How accounts are produced and read**

**George Smith**

Between the Lines

Eleanor MacLean

Black Rose Books (Montreal) 1982, 296 pp. \$12.95

Between the Lines (BTLs) is, as its cover says, a manual on "how to detect bias and propaganda in news and everyday life." It is a book that is designed to raise its readers' awareness of bias in news reporting, and more generally in the media. What it provides is a set of procedures for crap detecting.

The book, as well, concentrates on Third World issues. The last two chapters, in fact, are specifically designed to teach readers how to read between the lines of reports on the under-developed world, including parts of Canada. What it proposes as a technique is a left-wing interpretive frame. But more of that later.

First, funding for this project was provided by CUSO in the Atlantic Region and CUSO Development Education nationally, the Canadian Council for International Cooperation, the International Educational Centre, OXFAM and the United Church of Canada.

The fundamental problem in writing about ideology, propaganda, and bias is that such accounts are reflexive. They refer to themselves. A central tenant of BTLs is that, "In human communication, *all* the messages we receive will be the product of one of three types: someone's propaganda campaign, their presentation of information, or simply their point of view." (Italics in original) (p. 147) Presumably, the material and the analysis presented in BTLs is merely a point of view.

The argument in BTLs, however, is not presented merely as a point of view. Reading between the lines is described as an activity essential to understanding and controlling our lives. (p. 3) It also has to do with determining "when something is heresay, innuendo, or when it is fact" (p. 8) and with "distinguishing between error and truth." (p. 9) In chapter one, it is likened to applying the scientific method to the reading of news. But how is it possible for an account to be, on the one hand, merely a point of view; and on the other, scientific, factual and accurate? Surely science is intended to go beyond mere opinion, even politically correct opinion.

The failure of BTLs to deal with this issue is central to what is wrong with the book. The result is that it provides an ideological method for reading the news. I am not using 'ideology' here the way Eleanor MacLean defines it, as a kind of world view, but rather as a set of procedures and practices that are part of a much larger form of organized activity, usually found in bureaucracy.

Ruling ideology

The fundamental feature of ideology is that it begins with a concept. (See Figure 1) This conceptual frame, or set of conceptual practices, attends to the work at hand, to one or another administrative or bureaucratic problem. The existence of the concept provides the criteria for encoding reality. It selects what is to be looked at and how it is to be arranged in the account/report. In the process, people and events are abstracted from the actual social organization of life and given a new contextual relevance – one that meets the organizational

and administrative needs of a ruling apparatus. (This is also true of vanguard political movements on the Left.)

Ideology, on this account, does not reflect an individual's point of view. Instead, individuals come to see the world the way they do, come to have a particular viewpoint, because as in this case, their news reporting activities are part of a much larger, interrelated form of social organization. This includes the work of news gathering organizations, social scientists, government bureaucracies, politicians, advertising and public relations firms, the police, and so forth and so on. Together, these forms of work and the many practices they comprise are integrated into a particular form of organization; in this case, a ruling apparatus. This is social class conceived, not as a categorization of people and events, but as a living, breathing metabolism, a form of social [end of p. 279; continued p. 280] organization. The ideas, concepts, and interpretive frames/practices of this metabolism arise out of its work of ruling and administering people's lives. Under these circumstances, ideological practices and the practices of ruling are identical.

This, by the way, is exactly how the interpretive practices advocated in BTIs arise out of the work of CUSO. Because this work is located on the Left, its conceptual frames are typical of the analysis and the organizational work on the Left. BTLs starts not with how the news is organized in the practices of people, but with Left concepts. Its account, consequently, is ideologically produced. As a result, BTLs, in spite of all its efforts at being scientific reads like a Left conspiracy, detached, as only ideological work can be, from the world it attempts to describe. Apart from those prepared to adopt its moral stance, the analysis in BTLs will no doubt leave the Left unable, as usual to win over the "masses" to its "points of view." (Parenthetically, this is exactly the same position a part of the women's movement finds itself in over the issue of pornography, and for exactly the same reasons.)

In chapter one, under the heading "Method of Analysis", BTLs produces a version of the scientific method which, when applied to social life, ends up producing a series of categories, or interpretive frames as a method of analysis. Of necessity, these categories, whether they be the rate of unemployment, I.Q., the psychological conception of stimulus-response, social role, the gross national product, occupation, ethnicity, social values, and so on, attend to the work of ruling and administering society. The social science thus produced is positivist and ideological. What this form of science fails to understand is that social phenomena – and news, ideas, images, etc. are precisely this – are socially generated out of the activities of people, activities that have a particular social form sometimes framed as social relations.

### Real people

If this is how the society is actually put together, then any science of society if it is going to be scientific must be concerned with describing how social phenomena, including the media, are socially produced. The first premises of such a science would look like this, "They are the real individuals, their activity, and the material conditions of their life, both those which they find already existing and those produced by their activity. These premises can thus be verified in a purely empirical way." (Marx and Engles, *The German Ideology*). What such a science would produce would be an account of people's practices and their form of organization (i.e., social relation). A good example would be Marx's treatment of the commodity in the first chapter of *Capital*.

When it comes to media, there are two primary forms of activity people engage in. The first can be described as the social organization of its reading. These activities do not stand alone. Rather, they are integral to a much larger form of social organization, the social relation of class. Together, however, they constitute the social phenomenon called media. They bring media into existence.

While BTLs is primarily concerned with the social organization of the reading/viewing of the media, chapter three, entitled “This Message” is [end of p. 280; continued on p. 281] Brought to You By”, deals with how news is put together. The second paragraph of the introduction sets the frame. “If the old saying is true, ‘He who pays the piper calls the tune,’ we will have to find out who owns and controls the mass media in order to know what interests they might represent, and therefore, what point of view they are likely to reflect.” (p. 115) The purpose of this frame is not to find out how the media works, but to organize people against the “ruling class”. Science, in the process, is abandoned.

The point of view of the media, according to this account, reflects the owners’ interests. Ownership translates directly into control. At worst, this conjures up images of Lord Thompson of Fleet, for example, sitting all day with galley proofs for the many hundreds of newspapers he owns before him, blue pencil in hand, personally shaping the news. At best, we see him sitting at a super editor’s desk with a complete grasp of news events, dictating memoranda to local editors detailing the interpretive frames they are to use to report on the news as it breaks around the world. Now, while it is true that some owners of the media take some interest in how the news is shaped – Henry Luce of Time magazine is a good example – if we actually went and looked at how news is produced it would look quite different from this account.

What is class?

What has gone wrong? The problem, and remember that BTLs is a left-wing book, is how to develop a class analysis of the media. But what is class? BTLs treats class as a category with a check list. If a person, event, or thing can score enough points, it can be lumped into the category “ruling class”. What are the criteria on the list? Among others, “ownership of the means of production” figures prominently. So, how then is the media seen to be part of the ruling class? It can’t itself be said to own the means of production. But its owners can. Thus, the media through their owners get enough points to be included in the “ruling class”. What this interpretive frame, or set of procedures, requires is selecting out certain features of the media – ownership and control – abstracting them from the actual work of producing the news, and then using [this article continues ]

**Smith, G.W. (1989, Fall/Automne). "Where do we go from here?" AIDS ACTION NEWS!**

### **Where do we go from here?**

George Smith – Fall / Automne 1989, AIDS ACTION NEWS!

AIDS ACTION NOW! began with the struggle, for people living with AIDS (PLWAs), to get access to aerosolized pentamidine for PCP pneumonia. That was in February, 1988. Almost a year later, in January 1989, the Federal government agreed to release new experimental AIDS treatments, on compassionate grounds, through the Emergency Drug Release Program (EDRP). While the EDRP was not seen as the perfect solution, it looked at the time as though the problem of access to treatments was a thing of the past. That was before the fight for DDI.

Since the Vth International Conference in Montreal, where DDI was hailed as an important, less-toxic substitute for AZT, a struggle has been waged, both here and in the United States, for the release of the drug to people who cannot tolerate AZT. This effort has been directed mainly against the producer of DDI, the giant pharmaceutical company, Bristol-Myers.

The use of EDRP to obtain new treatments for AIDS has also given rise to another problem of access: some doctors are not prepared to use it in treating their patients. In some ways, this is not surprising. Doctors treating AIDS patients are pretty much on their own. For example, even through the AIDS epidemic is more than eight years old, there are still no standard treatments for many opportunistic infections, to say [p. 1] [continued p. 2] nothing of the lack of early intervention strategies for asymptomatic individuals. The Canadian medical establishment has not met its professional obligation to treat PLWAs/PLHIVs.

The use of the EDRP has made the struggle to get AIDS treatments a three-dimensional problem. Instead of becoming simpler, the situation has become more complex.

A. The federal government is not yet prepared to negotiate with multi-national pharmaceutical firms as a sovereign nation. It prefers to walk in the shadow of the United States Food and Drug Administration (FDA). This means that the Canadian release of new drugs is regulated by United States authorities.

B. The pharmaceutical firms are governed by their market interests, expect where they have to meet FDA standards for safety and efficacy. Improving the life-changes of PLWAs takes a back seat to making profits. AZT cost US\$10,000 per patient per year and alpha-interferon has recently been pegged at US\$12,000 per year. Last year, Burroughs-Wellcome, the producer of AZT, made the largest wind-fall profit in its history.

Nor are these corporations above using the AIDS crisis to put pressure on government to deregulate their industry. They hope that programs like "fast-tracking" the approval of drugs for AIDS will lead to lower standards of safety and efficacy in approving all new drug products.

C. And lastly, there is the problem of developing a backup system for doctors treating people with HIV infection. At the present time, the medical profession has failed to strike a common front in the fight against AIDS. Traditional methods and resources are not up to providing the necessary initiative and direction. Even the much touted Ontario Consensus Conference held last November has produced nothing in the way of a consensus on HIV treatment. Turf wars and personality conflicts abound. Different career-interests and levels of commitment on the part of physicians have left patients fending for themselves. Within Canada there is a virtual lack of any comprehensive system for the management of AIDS treatments.

Problems within the medical community are serious. For family doctors who are committed to treating people with HIV infection, the work is a money-losing venture. This is because PLWAs take more time,

require more paperwork, and, because HIV infection is a complex disease, their treatment demands more study and analysis by doctors. The costs of these kinds of extra services, however, are not easily recoverable from OHIP. Moreover, to make AIDS treatments a special OHIP category for payment of services would immediately identify people with HIV disease. This raises serious problems of confidentiality and anonymity.

For AIDS ACTION NOW! the increasingly more complex problem of getting treatment for PLWAs/PLHIVs raises the question, “What is to be done?”

At present, we are in the process of evaluating the effectiveness of the new federal minister of health and welfare. To date, the government does not seem interested in taking a firm stand with multinational pharmaceutical firms. We are also waiting to see if the minister will reorganize the Federal Centre for AIDS so that its mandate will include providing treatment backup services to doctors and their patients as part of the new national AIDS strategy.

The struggle for DDI has produced the first confrontation with a multi-national pharmaceutical company. There is no reason to believe that this will be the last one either. Unfortunately, community-based organizations have little leverage when it comes to forcing these corporations to take account of the needs of PLWAs and people living with HIV infection. The development of new strategies and tactics will be required for the future.

Fortunately, the situation is not totally bleak. The money that AAN! has recently received from the Trillium Foundation (thanks to those of you who play the lotteries) to establish treatment information exchange should be able to help provide treatment backup services to both doctors and patients.

These will include the publication of *TreatmentUpdate/TreatmentSida* and brochures like *Treatment AIDS* and *Testing AIDS* in both English and French, and hopefully other languages. This grant will also provide money to begin the monitoring of people taking various treatments (including complementary therapies) with a view to seeing which ones appear to be the most effective – a sort of community research initiative for Toronto. This kind of treatment information should be useful to both patients and doctors.

The Trillium money will also allow AAN! to set up meetings between doctors and PLWAs/PLWHIVs to discuss the latest developments in AIDS therapies. There is also talk (from the Vancouver PWA Society) of developing videotapes on HIV infection for doctors treating PLWAs and PLHIVs, and of computer-conferencing system of doctors (spearheaded by AAN!) to help with the exchange of treatment information. Lastly, there is the development and implementation of a treatment registry, part of AAN!’s seven-point policy paper, promised recently by the federal government.

It is not difficult to see that the problem of getting treatments for people with HIV disease is not over. In fact, the situation has expanded and become a good deal more complex in the year and a half of AAN!’s existence. Where do we go from here? That is something for us to decide together. What should be clear is that the problem of access to treatment has not been solved. [end]

**Smith, G.W. (1989, January). "From Pentamidine to Dextran Sulphate." AIDS ACTION NEWS! (p. 6)**

### **From Pentamidine to Dextran Sulphate**

AIDS ACTION NEWS! P. 6 – January 1989

George Smith

The Steering Committee of AAN! decided, at its meeting on January 10<sup>th</sup>, to phase out its highly successful Pentamidine Project. The Project, which has been going for nearly 9 months, has served PLWAs and HIV-positive individual living in Toronto. It has been used as a model to develop similar programs in Halifax, Montreal, London, Windsor, and Vancouver.

The Project began in response to the placebo-controlled trials of Aerosolized Pentamidine (AP) conducted by the federal government and Fisons, the pharmaceutical manufacturer, in Montreal, Toronto, and Vancouver. AAN! still opposes forcing people with HIV infection into trials of this sort as a way of getting the treatment they need. Because of the success of AP in preventing the onset of PCP pneumonia, AAN! undertook to make this treatment available to PLWAs who need it. Now a half dozen HIV doctors in Toronto are routinely administering AP to their AIDS patients. It is estimated that over 100 PLWAs in Toronto are taking AP as a preventative for PCP. To date the federal government's placebo-controlled trial of AP has only been able to enroll 75 experimental subjects.

The success of AAN!'s Pentamidine Project now means that apart from organizing a trip to Buffalo and getting the money to purchase the drug (not at all inconsiderable problems) people who need aerosolized pentamidine are now able to get it. And both the PWA Foundation and the AIDS Support group at ACT are helping individuals solve the problems of money and transportation. In fact, if someone needs AP these are the organizations people in Toronto should now consult.

AAN! will be continuing to have the same phonenumber for people who want to get in touch: 591-8489. It will also continue to help make promising treatments available to HIV-positive individuals and PLWAs. A new treatment that is attracting considerable attention in the United States and elsewhere is Dextran Sulphate (DS).

Dextran Sulphate is an experimental anti-viral treatment for HIV infection. This substance has been sold over the counter in Japan for years as a blood thinning agent. Unlike AZT, DS is not anywhere near as toxic and has many fewer side effects.

The federal government is planning a nation-wide placebo-controlled trial of DS towards the end of 1989. Already, a number of people in Canada are importing DS for their own use. In the United States AIDS support groups have developed buyers clubs to purchase substances like DS in bulk for those who need them. In Canada, however, the Food and Drug Act makes these kinds of bulk purchases illegal. Nonetheless, up to a three month supply of DS can be legally imported into this country by individuals for their own use.

AAN! is in the process of publishing a Dextran Sulphate bulletin to assist individuals who need this treatment to import DS for their own use. AAN! also very strongly recommends that individuals who want to use this treatment do so under the supervision of a physician. AAN's AIDS Update will continue to carry the latest medical-scientific information on the use of DS, including information of dosage, side effects, and similar topics of interest to users and their doctors. [end]



**Smith, G. W. (1990, Winter/Hiver). "In Memoriam – Tony Vigers 1942 – 1989). AIDS ACTION NEWS! (p. 6).**

**In Memoriam – Tony Vigers 1942 – 1989**

George Smith. AIDS ACTION NEWS! P. 6 Winter / Hiver 1990

Tony Vigers died last December. He had a devilish sense of humour and a wonderful sexual imagination. Over the last year, he worked for AIDS ACTION NOW! balancing the books, and making sure that our financial accounts were in order. This was not something new for Tony. After the bath raids in 1981 he joined the Right to Privacy Committee and worked as treasurer and as a member of the executive committee for five years until all the cases of those arrested had been won in court.

Tony lived with KS for nearly four and a half years before his death. He was one of the longest PLWA survivors in Toronto. Only in the last three months of his life did his health really deteriorate. He was born in England and came to Canada in 1948. He graduated from Ryerson with a diploma in business and accounting. A simple memorial service was held for Tony on December 14<sup>th</sup>. His ashes are to be scattered at his cottage in Muskoka in the spring. [end]



Smith, G. W. (1990, Winter/Hiver). "In Memoriam – Chuck Grochmal 1952-1990." AIDS ACTION NEWS! (p. 6).

### **In Memoriam – Chuck Grochmal 1952 – 1990**

George Smith. AIDS ACTION NEWS! P. 8. Winter / Hiver 1990.

Chuck Grochmal died February 3<sup>rd</sup>. He was an AIDS activist and founding member of AIDS ACTION NOW!. He called himself a "media slut" because of his unrelenting efforts, both in print and on TV, at promoting the interests of people living with AIDS. Contrary to what many people thought, this wasn't an ego trip for Chuck. He had a very strong sense of propriety that forced him to make sure that people and organizations were acting in the best interests of those they purported to serve. This sometimes annoyed others, but his efforts were principled, and often did a great deal of good.

His complaints, for example, were responsible for the installation of the chair lift at the ACT building. As a representative of AIDS ACTION NOW!, he got Canadian AIDS researchers to agree to having an open compassionate arm as a part of all clinical trials almost a year before ACT UP New York negotiated the parallel-track system with FDA. Besides writing his widely read column for *Xtra!*, he also did desktop publishing for AAN!. He produced the first design for this newsletter, and later produced two widely read AAN! publications, "Treatment AIDS" and "Testing AIDS". He computerized AAN!'s mailing list. Last fall he was elected to another term on the steering committee. Shortly afterwards, he was also elected to the board of Casey House. With his death, people living with AIDS lost a dedicated AIDS activist. [end]

**Smith, G.W. and Taylor, D. (1990, Juin/June). "A TREATMENT REGISTRY: One more step in managing the delivery of AIDS treatments." AIDS ACTION NEWS! (p. 1-2).**

### **A TREATMENT REGISTRY: One more step in managing the delivery of AIDS treatments**

George Smith and Darien Taylor

AIDS ACTION NEWS! P. 1 and p. 2. 24 Juin / June 1990.

AIDS ACTION NOW!, early on, investigated the serious problem of access to treatment, especially new, experimental treatments for people with HIV infection. Treatment has historically been delivered by a trickle-down arrangement. Treatment discoveries made by researchers were passed on to the specialists working in university teaching hospitals, who in turn passed them on to specialists in private practice, and who then passed them on to family physicians. Very often family physicians only found out about new treatments from pharmaceutical salespeople.

Doctors could have access to experimental treatments using the federal Emergency Drug Release Program (EDRP), but were left, along with the pharmaceutical company, to bear the legal repercussions, such as malpractice suits, that could arise from using unlicensed treatments. They also faced the prospect of having their hospital privileges revoked if they used unapproved treatments.

AAN! realized that it was necessary to put in place a new form of treatment infrastructure. The first step was publishing TreatmentUpdate/TreatmentSida to provide family physicians with up-to-date knowledge on AIDS treatment research. The second step was to create the Treatment Information Exchange (TIE) which is undertaking to develop a more elaborate system of treatment information for people with HIV infection.

Two TIE programs under active consideration at the moment are a computer-based system called MedLog for collecting treatment information over time from people living with HIV infection in order to determine what seems to be working for them, and a computer conferencing system for family doctors with HIV patients.

A third part of the treatment delivery system envisaged by AAN! is the creation of an AIDS Treatment Registry. Along with the Canadian AIDS Society and other community-based AIDS organizations, AAN! called on the federal government for the creation of an AIDS treatment register, which it has now [end of p. 1] [start of p. 2] promised to do.

The treatment registry is a management device ... [this article continues]