

"DDI saves lives" chant demonstrators

AIDS activists arrested in civil disobedience

TORONTO—On July 13 fifty noisy people demonstrated outside the Bristol-Myers office on Bay St. In a hastily organized noon hour picket, they were demanding the immediate release of DDI, a promising new anti-viral drug, through the Canadian Emergency Drug Release Programme-EDRP (see accompanying article).

At the same time seven AIDS ACTION NOW! members attempted to visit the Bristol-Myers office demanding to speak to company representatives about immediate release of DDI. Unfortunately, on instructions from their American head office they closed their office for the day at 11:30 am.

Those of us involved in the civil disobedience action chose to stay outside the Bristol-Myers locked doors chanting our demands until they were met. Bearing a banner reading "ACTION = LIFE" we placed signs on their doors demanding the release of DDI and chanted "DDI saves lives, AIDS ACTION NOW!"

Meanwhile property management for the building had called the cops. Fortunately the media arrived before the police making the action into a media event. But the police did eventually arrive. After warning us that they would charge us with trespassing if we did not leave we informed them that they were putting the interests of private property and Bristol-Myers ahead

of saving people's lives. We collectively refused to leave until our demands were met. Just prior to initiating our arrests the police unsuccessfully attempted to remove the media from the building. We chanted, "The Whole World Is Watching, Let The Media Stay!"

The police then carried the seven of us off one by one. This was the first AIDS activist civil disobedience action in Canada to result in arrests. A number of us went limp as a sign of non-cooperation as they removed us. They then placed us in an elevator and took us down to the basement.

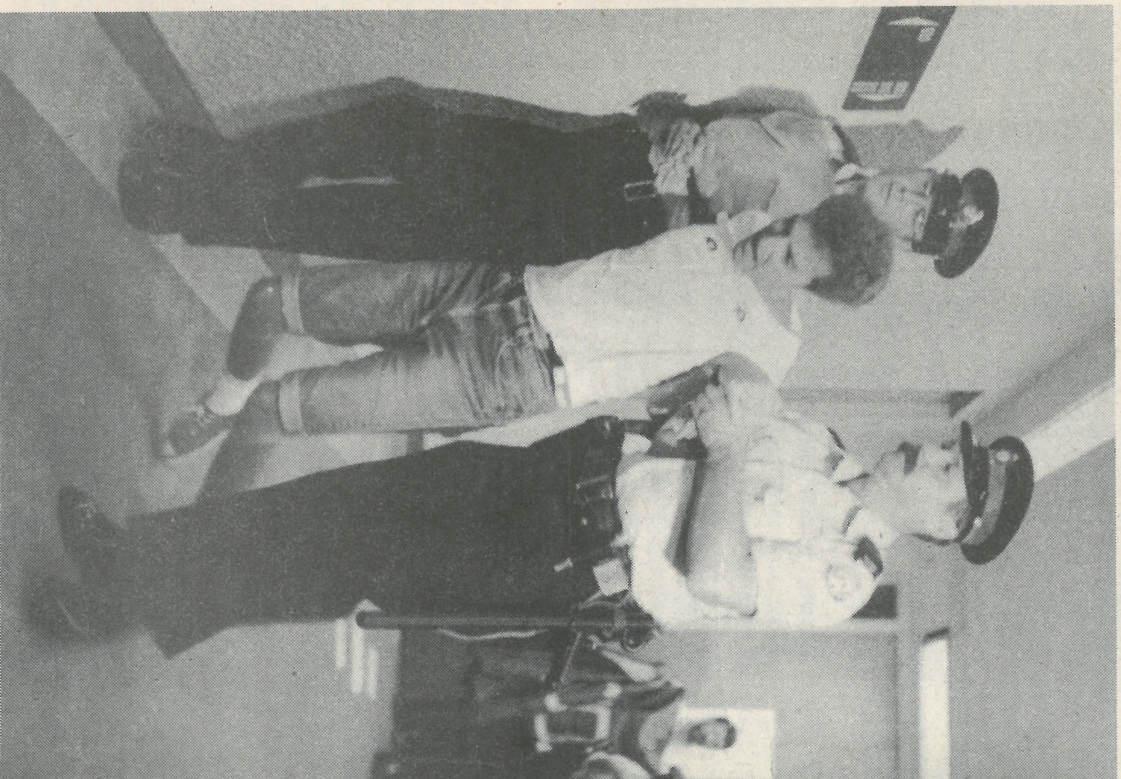
When Steven Maynard was arrested he was roughed up a bit and the arresting cop asked him "Do you have AIDS." When Steven asked why the officer stated "I'll get AIDS I want to know who gave it to me." When Brent Southin was arrested they painfully twisted his arm. When Brent said "Let go of my arm" the officer replied "I'd like to break all of your arms." The others arrested were Russell Armstrong, Patrick Barnholden, Gary Kinsman, Brian Leibel, and Lil Pearson. We were all charged with trespassing and given a stern lecture and then were driven in a police van and released a few blocks away.

With the support of AIDS ACTION NOW! (AANI) those of us charged are presently pleading "not guilty" to the charges. A possible court case on the basis of the

"defence of necessity"—that we had to break the law in order to try to save people's lives through securing release of this drug—could be a useful way to put continuing pressure on Bristol-Myers this fall.

Bristol-Myers continues to refuse to immediately release DDI through the EDRP. Continuing protests planned by AANI include leafletting the community calling for people to phone Bristol-Myers to register their protest (at 416-362-4281 or FAX 362-9249) and to boycott Bristol Myers products (including Bufferin, Windex, Javex, Miss Clairol, Exedrin, Ban, Nice 'n' Easy, Herbal Essence Shampoo, Mr. Muscle, Fleecy, and Body on Tap Shampoo). Bristol-Myers presently makes more than \$300 million a year in sales in Canada. If DDI is not released through the EDRP by early September more and larger civil disobedience and protest actions are planned. For more information write to AANI at Box 325 - 253 College Street, Toronto, Ontario M5T 1R5 or call (416) 591-8489.

Gary Kinsman and Brent Southin, members of the Bristol-Myers 7



Canadian AIDS activist Steven Maynard arrested at Bristol Myers demonstration.

Bristol Myers continues to hold back DDI

TORONTO—The July 13 AIDS ACTION NOW! demonstration (see accompanying article) was designed to protest Bristol-Myers' refusal to release, on compassionate grounds, a drug called DDI. DDI (dideoxyinosine) is a new experimental compound that generated much attention at last month's AIDS conference in Montreal as a potential treatment for HIV infection. It's a member of a class of drugs (known as nucleoside analogues) that include AZT, the only anti-HIV drug approved so far. However, many patients cannot tolerate AZT's toxicity, and DDI, said to be 10 times less toxic, promises to be a viable alternative anti-viral for AZT-intolerant people.

Last month, several Canadian doctors applied to obtain DDI under the federal government's Emergency Drug Release Program, or EDRP, designed to give terminally-ill patients access to experimental treatments on humanitarian and compassionate grounds.

But Bristol Myers, which makes DDI, refused to comply. In a telephone interview from New York, company spokesperson Susan Yarns said "it would be inappropriate to distribute the drug before safety data (from Phase I trials) is reviewed and evaluated," adding that the drug has only been tested in 90 people.

The drug company's refusal to supply the drug on a compassionate-use basis sparked the

demonstration and press conference at City Hall, joined by a mother of a person living with AIDS, Drs. Philip Berger and Doug McFadden, who both have large AIDS practices, AIDS ACTION NOW! called for a national boycott of Bristol Myers products and appealed to federal health minister Beatty to intervene.

But Michael Bork, a spokesperson for the Health and Welfare Minister's office, said "we really can't pressure the company in any direct way to produce a drug. What we can do is use moral persuasion to encourage them to produce drugs like DDI and we've let them know that it would be eligible under the EDRP. Short of producing it ourselves, that's all we can do." Bork added, "We accept that drugs are produced by companies and the company has to decide when they're going to make it available."

Bristol Myers, no doubt spurred on by the threat of a national boycott and adverse publicity, finally made their decision public last week, in a carefully-timed media manoeuvre. Before the activist's press conference had even ended, the firm's New York office, which had obviously anticipated the Toronto action, issued a short one-page statement to the media through a local Toronto public relations firm. In it, the company announced it may release DDI under the Emergency Drug Release Program when phase II trials for efficacy begin in September in both

the U.S. and Canada. Seriously-ill patients who fail to meet the trial's criteria would be eligible for compassionate distribution. This was initially seen as a victory for the activists, but in media interviews Bristol Myers officials maintained that the planned simultaneous compassionate release had in fact been in the works for some time, a claim echoed by drug regulators at the Health Protection Branch in Ottawa.

But both doctors and patients pointed out they had repeatedly tried to pin the company down on a date. "I was certainly never given any time frame by anybody at any time," said Dr. Michael Hulton, a primary-care physician in Toronto. "There was nothing in writing. There was no commitment."

Dr. Philip Berger feels the main reason for the protests was obscured in most media accounts. "Even though discussions with the drug company had been going on since April, the issue was the immediate release of the drug now, to people who desperately need it."

Skill, many journalists saw the company's promise of the drug by September as reasonable. Tom McFeat, a producer at CBC-TV's *The National*, which decided not to run the story, said "Bristol Myers said the drug would be available in September, and I think we have to assume, until we have some evidence otherwise, that companies generally tell the truth." But upon closer examination,

the promise of compassionate distribution in September, when the phase II trial is said to be starting, leaves many unanswered questions. Berger is quick to point out, "If Ottawa submitted the protocol today—which has not yet been submitted, by the way—at best, it would take at least five months to even begin the clinical trials, so they can't possibly start them until 1990." In order to mount a proper clinical trial, he explained, protocols need to be designed, reviewed by institutional review boards at trial sites across Canada, principal investigators appointed, patients recruited, etc...

When pressed on when the start of compassionate distribution of DDI would actually occur during this long process, officials at Bristol Myers are vague, referring only to the "start of phase II trials." There is no reason why emergency release should be dependent on drug trial approval or initiation.

Dr. Hulton is equally suspicious of the company's optimistic claims. "There is no possibility of phase II trials starting in Canada by September," he insisted.

Hulton agrees the drug should be released now for compassionate use, but strongly feels there should be some way to get at least some data on safety and efficacy.

"I don't think anybody really wants a new drug released without studying it," he says. "However, what EDRP does not have is a mechanism for reporting the ef-

ficacy of new treatments. You would need to draw up the right forms and do a research protocol, which they are not capable of administering. And the GP's, the family doctors that are requesting the drug by and large, don't have either the time nor the experience nor the expertise to do it. But it's not that difficult that it can't be done."

Regardless of when phase II efficacy trials begin in Canada, Hulton wants to see a firm commitment by Bristol Myers to release DDI for compassionate use in both the U.S. and Canada.

George Smith, who works with AIDS ACTION NOW!, is particularly concerned about people being forced into trials to get DDI. Not only do Smith and other activists see this type of medical coercion as unethical, but impractical as well. "If people are forced into a trial to get treatment, then when some other drug comes along, they'll jump to that one or unblind the drug they're being given to find out what they're taking, which really interferes with the efficacy of the trial," Smith says.

Colman Jones

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