THE ROLE OF GOVERNMENT AND SPECIAL INTEREST GROUPS IN KEEPING INFORMATION FROM THE PUBLIC: A JOURNALISTS PERSPECTIVE

LE ROLE DU GOUVERNEMENT ET DES CERCLES INTERESSES DANS LA NON-DIVULGATIONDE L'INFORMATION AU PUBLIC: UNE PERSPECTIVE JOURNALISTIQUE

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ABSTRACT

Canada has been and continues to be a closed society. Information is power and that power is tightly controlled in the hands of small groups in Canada.

This paper will discuss the great reluctance of government and industry to make information on food and drug testing public despite the tact that it dramatically affects the daily lives of all of us.

It will also attempt to show that the assumptions supporting continued confidentiality of information, as in the exemptions in Bill C-43, are not based on well thought out economic or security reasons but on the specious desires of particular vested interest groups to maintain power positions in society.

RESUME

Le Canada a toujours été et continue d'être une société fermée. L'information représente le pouvoir et ce pouvoir est rigoureusement controlé par certains petits groupes ou organismes au Canada.

L'auteur discutera de la grande réticence du gouvernement et de l'industrie à divulguer l'information concernant les tests sur les drogues et aliments, en dépit du fait que cette information affecte de façon dramatique notre vie de tous les jours.

Il montrera également que les prétentions en faveur de la confidentialité de l'information, comme le démontrent toutes les exemptions du Bill C-43, ne s'appuient pas sur des arguments économiques ou sécuritaires bien réfléchis, mais plutôt sur les efforts spéciaux de certains groupes ou organismes à protéger leurs droits acquis et à maintenir leur position de force dans la société.

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Like many of you, information is my stock in trade! Getting information is the key to my functioning effectively as a journalist; however in Canada it is, always has been and will continue to be, very difficult to obtain information that government and special interest groups don't want the public to have.

Journalists and the public cannot get access to information that corporations file with the government in order to gain approval for new drugs, food additives, pesticides and a host of other commercial products. There may be a very good reason for this based on an historical examination of data that has emerged in the U.S., which has more liberal information access laws than we do.

Over the past two decades there has been well documented rigging of scientific tests in both the drug and chemical industry which benefitted the profitability of the corporations to the detriment of human health and the environment.

Let me give you a few examples.

First, there was the Kevadon scandal in the early 1960's. It's better known now by its generic name Thalidomide. This is a sad chapter in Canadian drug regulatory history ... despite many warning signs from Britain, Germany and Italy the drug was approved for sale in this country on the basis of test data supplied by it's North American distributor, Merrell.

It was a crusade led by Baltimore pediatrician, Dr. Helen Taussig, against the combined weight of the U.S. Food and Drug Administration and Merrell that led to the discovery of severe birth defects.

However, little action occurred to reduce distribution of the pills in clinical trials in the U.S. until Morton Mintz of the Washington Post broke the story in July 1962. He showed that there was an indisputable link between pregnant women given Thalidomide and the birth of deformed babies. Shortly afterwards the drug was withdrawn from distribution here.

This is not an isolated case of a drug released as a result of suspect clinical tests and the driving zeal of corporate marketing specialists. The list of similarly marketed drugs, later found to have harmful side effects, is large and continues to grow and calls into question the entire process of drug regulation.

Just before the Thalidomide scandal, Merrell produced and marketed a widely touted cholesterol reducing drug called MER-29.

It seemed like the perfect answer to the burdgeoning concern about heart attacks and elevated cholesterol levels. In the U.S. almost 100,000 people were given the drug in widespread clinical tests in 1960.

It wasn't until early 1962 that FDA scientists were able to show, after a review of suspicious data supplied by Merrell, that people taking MER-29 were 3 times more likely than those not taking it to develop cataracts in their eyes.

The FDA began an investigation of Merrell's testing procedures and found that its clinical screening tests were doctored to hide serious side effects that showed up in the company's scientific tests which it had submitted to get the drug approved. In 1964 criminal charges were filed against the company and three senior employees for rigging laboratory test results and lying to the FDA about the potential health threats posed by the new drug.

The company and its officers pleaded no contest to 8 charges and were fined $80,000 which when compared to its sales of $180,000,000 that year were a mere drop in the bucket. However civil damage actions against Merrell by more than 300 injured people forced the company to pay millions of dollars in out-of-court settlements. The cases were settled out of court so that no legal precedent would exist in the U.S. to serve as a basis for similar actions against the company in other countries.

Now in case you might think this was an isolated case from 20 years ago and ethical considerations in the industry have improved listen to this.

In 1979 Smith Kline and French introduced Selacryn, promoted for treating high blood pressure, into the U.S. market. Nine months later, after 300,000 patients received the drug, it was withdrawn from the market. 486 cases of liver damage, including 34 deaths, have been reported in patients taking the drug.

The real toll may be much higher because the 486 cases are from reported or known incidents, and it's assumed that the real total may be well in excess of 1,000. Ralph Nader's Health Research Group, in Washington D.C., found through U.S. Freedom of Information requests that Smith Kline and French had been in violation of federal law by not reporting adverse reactions as quickly as required.

In a speech to the American Association for the Advancement of Science in Toronto earlier this year, Sidney Wolfe the director of Ralph Nader's Health Research Group, said "200,000 patients ... were needlessly exposed to this drug

because of (the Company's) delays in reporting to the FDA ... and the consequent delay in banning the drug. In other words, by trivializing the risks (to the FDA and Doctors) but emphasizing the benefits through major advertising campaigns, SKF sold several million dollars more of Selacryn after it knew but didn't tell of the serious dangers of the drug."

According to a recent New York Times story Smith Kline and French has been hit by 50 lawsuits from individuals or survivors who were adversely affected by the drug.

In Canada, clinical trials with Selacryn exposed 40 people to the drug for 12 weeks according to a spokesperson for the Health Protection Branch in Ottawa. She said none of the problems associated with the drug in the U.S. showed up in the 40 Canadians. However when asked for the names of the Doctors conducting the trials I was told that only the drug company could release them. Because of medical confidentiality the names of patients given the drug are not available. Because of the Federal Government's information policy I was not able to independently verify from the doctors who administered the drug, that there were indeed no health problems linked to Selacryn.

Other drug horror stories abound ... Bendectin the anti-nausea drug used by thousands of pregnant women annually has been linked like Thalidomide to deformed children.

An antibiotic -- Albamycin T -- was withdrawn from the U.S. market but is still available in Canada under the name Panalba.

Another antibiotic -- Chloromycetin -- was widely misused because of aggressive and disceptive marketing and many unnecessary deaths from aplastic anemia resulted.

More recently, The Dalkon Shield an intra uterin device to prevent pregnancy caused widespread infections among women users and many deaths as well before it was withdrawn. Again it was overly aggressive marketing along with a conscious minimizing of emerging health problems that caused so many health problems.

Most of these horror stories of corporate greed were uncovered by U.S. journalists able to get access to information which in this country would only have been shared between Government and the drug companies involved.

Let me now discuss another shortcoming of drug industry which, while less life threatening than those I've mentioned, costs consumers hundreds of millions of dollars annually. I'm referring to useless products ... drugs we all take which the

U.S. Food and Drug Administration says have not been proven to have beneficial effects.

Recently the Washington based, Health Research Group, published a book called "Pills that Don't Work" detailing the lack of proved effectiveness of 610 drugs with sales in North America of more than 1 billion dollars. Many of these drugs are also sold in Canada and I'd like to be able to scrutinize the test data that was filed with the Canadian Government to win marketing approval for these drugs.

But no one can get this information! The federal government says information is the property of the corporations submitting the data and that it is not empowered to release it.

This is the nub of my presentation ... imagine a situation where corporations can willfully endanger public health, or deceive us into spending vast sums of money for useless products, with their inherent side effects, and we have no ability to independantly examine the data filed with the government to get these products approved in the first place.

This has been the case in Canada, is now the case, and will be the case if exemptions under Sec. 20 of Bill C-43, the proposed Access to Information Bill, are not eliminated prior to third reading.

One of the things that has long bothered me is the constant interchange of personnel between government and industries which are regulated by it. Yet any attempt I've made to determine the working histories of people in key government regulatory jobs has met with rejection.

It comes as no surprise to me that the positions of the Pharmaceutical Industry and the Federal Government on release of drug information are the same. Our society knows very little about the relations between special interest groups of Government policy. In fact special interest groups, of which the Pharmaceutical Manufacturers Association is one of the most powerful, are often the authors of Government information policy. I doubt whether I'll ever learn if this is indeed the case on the non-release of drug testing data because again the Government would not release this information to me.

Now in case you think I bear a grudge against the drug industry let me assure you that in my mind it is no different than the chemical or food industries which also lean on the Government to withhold information on products which are approved for sale to the public.

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I'm sure almost everyone has heard of the recent practices of the U.S. based Industrial Biotest Laboratories which is charged with fraudulently rigging safety tests on 205 chemicals, mainly pesticides. Yet our Federal Government refuses to release a list of these suspect products claiming its lawyers have told it that the information are industry trade secrets. This is patent nonsense! I'm grateful to Toronto lawyer, Heather Mitchell, for pointing out that it is not possible to have trade secrets on false information.

The Government's information policy could adversely affect the health of thousands of farmers and gardeners who are exposing themselves to potentially harmful products.

Equally outrageous is the fact that the Government will not allow the public to openly scrutinize the re-testing of the suspect chemicals ... we have no choice but to accept the word of the same Government people who were fooled by Industrial Biotest in the first place.

I've used these examples to show that access to Governemnt held information is fundamental to a free and open democratic society. Unfortunately in this country special interest groups and governments have shared the same mindset over the years to successfully keep most of this information from us. And I'm not very hopeful that Bill C-43 will in any way substantially lower these traditional barriers to information.