Standing Committee on Health Care

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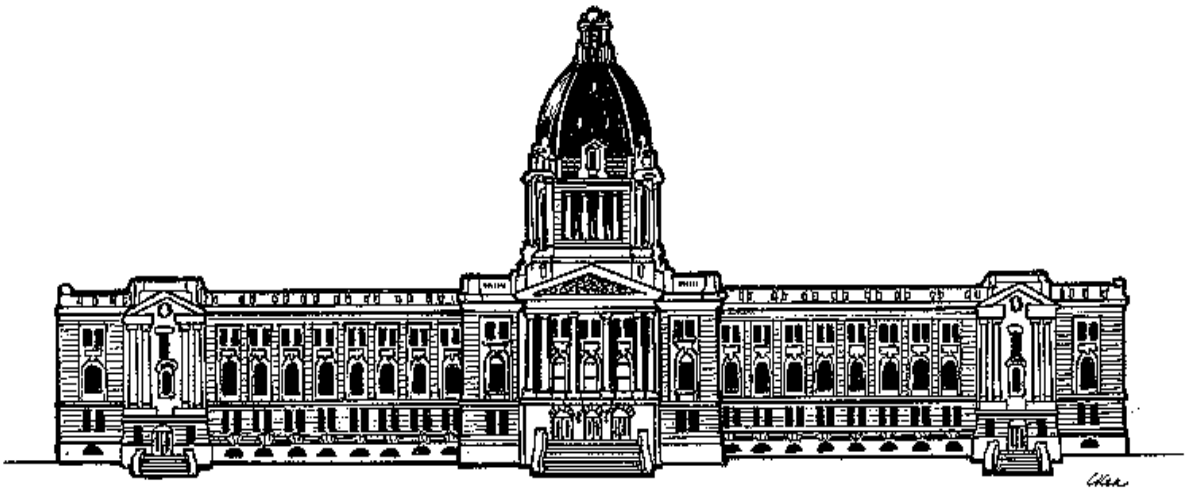

Legislative Assembly of Saskatchewan

Twenty-fourth Legislature

STANDING COMMITTEE ON HEALTH CARE
2001

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Published under the authority of The Honourable P. Myron Kowalsky, Speaker

The committee met at 11:01.

The Chair: — Okay, if we could ask our presenter to come and have a seat up here, Sharon.

I just have a few opening remarks if you want to have a chair. We're copying your presentation and we'll each have a copy of it soon. I just wanted to make a few opening remarks that this is the Standing Committee on Health Care and I am Judy Junor, the Chair of the committee. It's an all-party committee. The other members of the committee — Dr. Jim Melenchuk is the Vice-Chair, Andrew Thomson coming up right there, Warren McCall, Buckley Belanger, Brenda Bakken, and Bill Boyd is on his way, and Rod Gantefoer.

The committee was formed at the direction of the . . . by motion of the Legislative Assembly and its first order of business was to receive responses to the Fyke Commission. We report back to the legislature on August 30, so we're sitting for the month of July here, having public submissions to the response to the Fyke Commission.

And we've given people 30 minutes. Usually what they've done is . . . that's to include questions. So people have given their presentation and then there may be questions from any of the members within the 30 minutes.

So if you want to introduce yourself for the record, you can begin your presentation.

Ms. Laporte: — Thank you for the opportunity, Mr. Chairman or Madam Chairman, and members . . . Mr. Chairman, and members of the committee.

My name is Sharon Laporte and I speak from the perspective of a nursing background. I'm post-graduate trained in two areas of nursing — the operating room and occupational health with a special interest in industrial toxicology. I worked in supervisory capacities in both specialty areas in major acute care hospitals and in industry, as well as for the Government of Saskatchewan. However I have not worked in my profession since 1987 owing to incapacitation arising from exposure to toxic chemicals, primarily those which attack the brain, that is to say neurotoxic substances.

I speak today as one suffering from what has been described as a newly emerging group of environmental illnesses — multiple chemical sensitivities, chronic fatigue syndrome, and fibromyalgia.

I have come before you today to speak not so much about a crisis in health care but about the larger picture, that which is fuelling the fire as it were, namely toxic global industrial pollution. We have become wittingly or unwittingly the poisoned planet's poisoned people, period.

This is not my humble opinion but rather the opinion of eco-toxicologists the world over. It has also become my experience personally.

Quantities of the following neurotoxins have been identified in my blood and urine by FDA (Food and Drug Administration) approved industrial toxicology labs in the US (United States). These include arsenic, cadmium, lead, mercury, nickel, thallium, tin, benzene, toluene, ethyl benzene, xylenes, styrene, triethylbenzenes, dichloromethane, chloroform, 1,1,1-trichloroethane, trichloroethylene, tetrachlorethylene, and dichlorobenzenes.

And while I have not been tested for the presence of agricultural chemicals as being present in my body, consequently I cannot say whether I'm harbouring these as well.

What this array of substances has in common is that each and every one of these is a nervous system poison. The message given by ecotoxicologists is unmistakeably clear: clean up the planet or forfeit human existence. The human race and their educated opinion is in fact an endangered species. Such is the opinion of eminent ecotoxicologists whose book — and I highly recommend it — *Our Stolen Future* says it all.

It explains in detail how biologically active synthetic chemicals are capable of affecting human sexual development, including the precipitation of gender bending; affecting behaviour, intelligence, and the functioning of the immune system, including the development of cancer, through a unique process specific to endocrine disruption, which incidentally does not take the same course as cancer resulting from toxic substances which are not hormone disruptors.

It is noteworthy that Dr. Theo Colburn of the International World Wildlife Fund and co-author of *Our Stolen Future* was a presenter at the federal government's Standing Committee on Environment and Sustainable Development and has had included a portion of her presentation in the committee's May 2000 document, *Pesticides — Making the Right Choice for the Protection of Health and the Environment*.

It is also noteworthy that the document produced by the committee states, the committee recommends that Health Canada take the necessary steps to bring about legal recognition of multiple chemical sensitivity syndrome.

This statement appeared in bold print on page 55 of the document. Health and well-being cannot be viewed, acquired, or maintained as separate and apart from the environment. We're all biological beings and thus must respect our biological limitations. Regrettably, as a society, we have failed dismally in this regard.

Personally I believe that the health care crisis in which we now find ourselves is more about the philosophy that we have adopted as evidenced by our choices, although unwittingly in some respects by working against nature rather than with it. Thus we find ourselves in overwhelming circumstances as our society . . . as our societal institutions become unravelled for the lack of the ability to adequately cope.

There is a larger crisis looming than the one which we presently find ourselves. Unless we begin to treat underlying problems rather than simply masking the symptoms of disease with pharmaceuticals, I fear our present unfortunate situation will culminate in active euthanasia. There will be just too many sick people to deal with.

The Science Council of Canada predicted that by the year 2031, we would be involved in euthanasia. By the way that prediction was made prior to the advent of AIDS (acquired immune deficiency syndrome).

Since the end of World War II, the way in which we have ignored our human biological limitations is presently bearing fruit in terms of chronic degenerative disease. We have ignored the fact that our destiny is unmistakably linked to the eco system. Fish were not designed to live out of water; similarly we were not designed to live in a toxic, chemical, or electromagnetic soup.

In short, whatever we do to the environment we do to ourselves. The supplies to our bodies, ourselves, and the external eco system of which we are an integral part.

Eco toxicologists have much to teach us about just how fragile and delicate the balance is and how imperilled we now are. Regards the future of medicine, there is a new model emerging that seeks to incorporate conventional medicine, natural medicine, industrial toxicology, and environmental medicine known as functional medicine.

This medical model seeks to find the underlying cause of health problems before organ damage has occurred. It seeks to find and eliminate the underlying cause of disease. It is that which is going to affect the paradigm shift for our betterment overall, wherein we will move beyond pharmaceuticals and the conventions of our modern day.

However, the dinosaurs of our times remain strong and they have been given a licence to print money by virtue of the fact that much of their control exists into the realms of medical educational and research, and thus they are in a position to educate people to fit into the system . . . into the existing system, one that leaves little or no room for anything other than that which will maintain their extended profit margins. And I'm speaking of the corporate interest of toxic chemical manufacturers, both industrial and agricultural as well as pharmaceutical.

Health care should be the prerogative of good government. And although I do not personally subscribe to partisan politics, my hat goes off to those men and women who have entered political life for the betterment of the people.

In any case the government has become involved in footing the bill not for a health care system but rather a sickness management service, based on outdated models of diagnosis and treatment which do not respect the body's biological needs or limitations.

In order to become a nation of healthy people, government must free itself of the influence of the corporate world, of international polluters who have profit margins and not the well-being of populations as their primary interest. I believe that it would become highly insightful for government to take a proactive role in examining course curricula in our medical and dental schools, given the warnings by the eco toxicologists and given the planet's unprecedented state of pollution.

The education of our health care providers is regrettably not in step with the needs or the state of contamination as it exists in our modern industrial society. Personally I find it telling that in a world burdened as never before with highly toxic substances, which have been ubiquitous, our doctors or dentists have no knowledge of either industrial or environmental toxicology. It's like having loans officers at the bank that have never learned to count.

What to me is even more shocking is that course curricula are also devoid of nutrition courses, let alone super nutrition — the kinds of super foods that are keeping many of the people in the entertainment world young, beautiful, and filled with vigour beyond their years. These super foods are absolutely essential to overcome the effects of the body burdens of toxic substances. It is true that we are what we eat. The body rebuilds itself with that which we feed it.

We would never think of putting water into our gas tanks, but we don't give any thought to putting highly toxic substances into our bodies via the food chain, or through the air that we breathe, both indoor and outdoor at home and at work. Not to mention the water and other things that we drink.

People in advanced nutritional sciences are saying, without hesitation, that a cup of spinach in great-grandma's day was worth between 50 and 75 cups more in terms of nutrient value compared with the spinach of our day. What does that say about the depletion of our soils by the persistent use of chemical fertilizers and the like? To me it says we must embark upon change; the sooner the better. Half-hearted measures, quite simply, will be too little, too late.

Although I have provided a rather long overview of what I see as being integral to our failing health as a nation, I wish to point out that I came by this view based on my personal experience as a person who spent 10 years with misdiagnosis, underwent useless surgeries, as well as psychiatric admissions.

I have on occasion, following neurotoxic exposure, been rendered crazy from chemicals. For a given period of time, I have experienced everything from suicidal depression to suicidal behaviour. I have experienced neurological reactions that characterize road rage. I have suffered the loss of my children and extended family through estrangement as a result.

This illness eventually cost me my marriage, as marriages under the burden of stress from chronic illness require support, which simply did not exist for us. My ex-husband was continually blamed for my condition. Nothing could have been farther from the truth. My career, my education, my ability to contribute to society, have all gone by the wayside. And of course I have forfeited my health in the process, living with undiagnosed, unresolved poisoning of the nervous system.

I wish to point out that when the system does not acknowledge one's illness within its highly structured social model, and you therefore fall through the cracks in the system, you will not be perceived as credible. And the end result is that you become abandoned, betrayed, and denied, not just by the system but by those closest to you.

If they continue to stick by you, they must live with the threat that the system is wrong. And since that is too, much too

threatening for most people's defences, you lose them. It's easier for them to avoid dealing with the problem than confronting it on an ongoing basis with no end in sight.

In 1992 my next-door neighbour's use of weed killer destroyed my house. My parents arrived to find me in a hysterical state. They believed that I had been physically assaulted, such was my condition of neurogenic shock. They tried to help me by taking me to the local hospital, but the chemicals, having kindled the limbic system of my brain, prevented me from being able to tolerate the emergency room.

Then they endeavoured to help me recover in their own home. But alas, my nervous system had been so stressed by the toxic assault, I could not bear the remnants of the natural gas relative to pilot lights on their gas appliances. In the end they took me to my daughter's residence in Regina. After having spent in the neighbourhood of 35,000 to be sure that the house was safe for me, a single application of chemicals on their lawn ended it all.

(11:15)

Environment Canada advised that the chemicals would not likely break down for well over 100 years. Since it had become affixed to surfaces inside the house, their advice was that I move.

After the spraying incident I had to sleep on the sundeck, and I did so up until mid-December, when other neighbours, fearing that I would die from exposure, invited me to use the third floor of their home for sleeping.

Thus I have become an environmental refugee, essentially living out of boxes from that time on.

At the present time I live on the Canada disabled pension of less than $900 a month, despite the fact that I contributed to a long-term disability pension plan while employed by the Government of Saskatchewan.

I have been disenfranchised from my duly entitled benefits as have numerous others who have lifelong claims. A number of these people are known to me personally, and are also MCS (multiple chemical sensitivity) victims. Without naming names, a former associate deputy minister of Labour looked into my case after having examined the facts closely, to ask why I was not receiving my long-term disability benefits. He was told that it was political.

In any case, the fact that the long-term disability pension plan went missing 15 million, as reported by CBC (Canadian Broadcasting Corporation) in 1995, has not cut any ice in terms of investigating what happened to the money. But you don't have to be very good at math to realize that this in itself could provide a motive to disenfranchise those with truly lifelong claims.

Besides this impoverishing situation owing to the fact that the present system is hinged on synthetic pharmaceuticals, I find myself entirely outside of medicare. Never mind a two-tiered system — what this system has to offer is not safe for me and serves to worsen my symptoms. I actually become ill in hospital settings, as do other multiple chemical sensitivity victims. Heaven forbid that I should ever require trauma surgery.

I have spent approximately $60,000 over the past 10 years in medical needs, including diagnostics in the United States. About 50 per cent of the money came from the help of friends, friends whom I pray one day to repay for their generosity and kindness.

Besides owing my friends, I also owe outstanding fees for medical and dental services obtained in Canada and the United States.

None of this seems right to me. We hear a great deal about two-tiered medicine today. However, I don't suppose that unless you know about multiple chemical sensitivity that you would ever dare to presume that in Canada there are people for whom there is no care available owing to the failure within the system to provide for their unique needs.

Multiple chemical sensitivity has been known by a variety of terms over the years, including total allergy syndrome. This illness is no longer the mystery that it once was and is far more complex than that of allergy.

Academics recognize MCS as primarily an acquired neurological disorder. Exposure to various toxic agents which classify as neurotoxin substances — whatever their other classifications may include — comprise the exposure history of MCS victims. Neurotoxins are nervous system poisons. Some are solvent based; others comprise heavy metal compounds such as mercury.

In 1992 Health Canada held a workshop on MCS and produced a document titled *Multiple Chemical Sensitivities and Their Relationship to Psychiatric Disorders*. The 1990s were a time when this illness began to be placed in its proper perspective as one stemming from problems associated with nervous system poisoning. The document produced by Health Canada had a very telling statement about the brain spec'd image scans of the chemically sensitive, and I quote:

> Spec'd scan imaging in drug abusers bears the closest resemblance to that which is being found in the chemically sensitive or chemically exposed patients. This may not be surprising, considering the neurotoxic effects of drug abuse and the known neurotoxic effects of certain kinds of chemical substances, exposure to which is frequently reported to cause neurocognitive symptoms in the chemically sensitive patient.

Poisoned neuroreceptors and neurotransmitters negatively affect behaviour, mood, learning, alter perception and negatively impact health overall. Still, conventional medical schools are not teaching anything about this problem.

In 1994 the Institute for Science and Disciplinary Studies in Massachusetts had this to say about MCS. Multiple chemical sensitivity is one of the fastest growing, unsolved health problems in the United States and the world. It is a chronic, multi-system, environmental illness in which individuals sensitized by past toxic exposure suffer severe disabling and sometimes life threatening reactions to subsequent exposures of low levels of common indoor and outdoor environmental

chemicals. Example: exhausts, pesticides, fragrances, solvents, and other chemicals.

The chemical reactivity often leaves them physically incapacitated, socially isolated, economically devastated, and emotionally and spiritually drained. Few health care practitioners are trained to diagnose or treat multiple chemical sensitivity or its precursors. MCS -accessible offices of the non-MCS health care needs are almost non-existent. Policy and its administrators have yet to catch up with this exploding problem, so disability and other society-wide services most often, either directly or indirectly, exclude the MCS population.

Neurotoxicity is a very widespread condition in modern society. It ranges from severe cases; such as occur in occupational exposures to suffocating agents in solvents to mild cases in which the sufferer does not know that he or she is being affected. Neurotoxicity screening has been developed and has been recommended for use in occupational health programs in the workplace for well over a decade. Some of the questions surveyed relate to memory, concentration, interest span, planning, common sense, sleep problems, having nightmares, vision-related problems, hearing-related problems, alterations in one's sense of smell, numbness and tingling sensations in the extremities, changes in handwriting, tremors, changes in gait — the way we walk, muscle spasms, speech-related changes, are all among the signs and symptoms.

I have gone on to suffer from chronic fatigue syndrome since having petrochemically-based dental material installed. The dental material is presently severely incapacitating my endocrine system and I require between 4 and $500 a month in natural supplements, including brain hormone supplements and thyroid. Without these products, I become totally incapacitated and I find it an all-out effort just to accomplish personal hygiene. I have also been given to experiencing blackouts and seizures, heretofore not a part of my reactions prior to the installation of plastic in my teeth.

I had been afflicted with fibromyalgia while living on Vancouver Island. The fibromyalgia problem resolved after I took myself out of the range of the electro-smog from various communication towers and moved to an apartment with less electrical hazards.

No doubt you have noticed that a number of my front teeth are missing and affecting my pronunciation. Although it tests one's vanity to appear in public in this way, I felt that what I wanted to share with you was far more important than notions of personal vanity. Regards the situation of my teeth — those missing and those present — the lack of understanding about the needs of the chemically sensitive to absolutely avoid synthetics has placed me in this dreadful situation that you witness here today.

To date, I have spent about $45,000 on dental care. Now to remedy the present situation, I'm in need of very high-tech solutions, which will cost in the neighbourhood of about $75,000. Dentures are not an option because of chemical sensitively. But what is more, according to my dentist, extraction of the teeth in my case could very well be life-threatening. Also my dental work will have to be done outside the province. Where does it end? At the grave?

It is noteworthy that when the tooth fairy took all my baby teeth, not a single one had any decay. My first exposure to neurotoxic chemicals came during adolescence. I lived on a farm that was subjected to heavy agricultural chemical spraying. The chemical exposure took a toll on my teeth. As an adolescent, my teeth began to decay in an unprecedented fashion, the same summer as my legs ached and ached until I wept as a result of the unremitting pain. The family doctor did not know what was wrong and placed me in a body cast because he thought that perhaps there might be something wrong with my back.

While being invested for neurotoxicity in the States, I also learned about the nature of the leg pain I experienced as a girl growing up in rural Saskatchewan. Since I refused to wear shoes during the summer and went barefoot, the agrochemicals were absorbed through my bare feet and had accumulated in the long nerves of my legs. At the same time, I went from no cavities to several cavities in a very short period. Agrochemicals are designed to destroy and disrupt enzymes. The enzyme Ptyalin plays an important role in oral heath.

Many years later, while on staff at the Plains Health Centre, I suffered the same disabling leg pains, as did many of my nursing colleagues. In fact, many of us resorted to wearing the hospital's anti-embolectomy stockings over our regular support hose while on duty because our legs just wouldn't quit aching.

At the time, I did not know that the hospital was insulated with UFFI, urea-formaldehyde foam insulation. Formaldehyde is a neurotoxic substance which has been determined by the American National Research Council to produce neuro-cognitive and neuro-psychiatric symptoms at one-twentieth of one part per million. Three parts per million was the Canadian industrial standard at the time that I worked at the Plains. One part per million is the present industrial standard.

It is now known that there are no safe levels for exposure to solvents. Formaldehyde is solvent based. Formaldehyde is also a known carcinogen.

Internal varicose veins were blamed for my aching legs and I underwent surgery to strip them. But no one could explain the nosebleeds that I kept having at work or why I was plagued with nightmares and severe clinical depression.

I took myself to a psychiatrist but he was of no help. The drugs he prescribed caused me to fall asleep while at work and I was anything but a safe nurse at the time. But I could not convince anyone that I was not in shape to be working.

Within two years . . . within two weeks after the surgery the groin incisions opened but there was no infection. Something had delayed the wounds from healing. That was in 1978. It would not be until 1992 that I would learn the essence of the problem.

In 1992 I made arrangements to visit an American forensic neurotoxicologist in hopes of accruing evidence to obtain my long-term disability benefits at the cost of about $10,000 to me personally. Over a period of about 16 hours of intensive . . . of extensive testing, a number of neurological deficits were

mapped and put the missing pieces of the puzzle into place. I was suffering from neurotoxicity, a poisoned nervous system, as well as multiple chemical sensitivity and disabled from both.

As an adolescent and as an adult, I had experienced repeated neurotoxic exposure and developed MCS.

Then at one of the province's technical institutes I had finally succumbed all together as a result of exposure to a cyanide-and-toluene-containing compound determined by the Saskatchewan Department of Labour to be in excess of 100 times the industrial limit. This product was so toxic that the international toxicologic community endeavoured, although without success, to have it taken off the market.

It has been determined that I have lost 25 points off my IQ (intelligence quotient)as a result of workplace exposure. The other neurological deficits that I have incurred go beyond the time which allows for this presentation.

However, in view of the fact that there were about 1,500 students enrolled in the school and about 350 staff, I am of a mind that a public inquiry was called for. If the nurse lost 25 points off of her IQ, what about the students and what about the other staff?

In the real world, cover-up and ignoring the facts are now . . . are how the game is played. Because the way the system works, it would rather ignore the facts than deal with them.

After having the Saskatchewan Department of Labour investigate the problem, my position was axed. In fact the administration went so far as to procure an exemption from occupational health and safety law to abolish the position of the nurse at the institute.

To date, it remains the only technical institute in Saskatchewan without a nurse. Perhaps to get to the bottom of things, in view of the seriousness of that which we are confronting, a better approach would be the kind of truth hearings that were held in South Africa following the collapse of apartheid, especially in view of the threatening nature of unearthing details of these toxic tragedies.

However, the most devastating of all is that two of my children have also become chemically sensitive, no doubt owing to the neurotoxic substances that I passed on to them in the womb. They have not yet become totally incapacitated but the signs are there, so the writing is on the wall for them.

Perhaps worst of all . . . that the stigma they carry from my situation is so great that one of them cannot acknowledge or speak of his problem to anyone, while the other is able to confide in me. He has an IQ of 139, but because of MCS it is unlikely that he will ever reach his God-given potential. Because he does not feel well in buildings, he has chosen to work in the wild and it is really all that he can manage. Despite his high IQ, he simply cannot focus and gave up university. He tree plants, unable to manage anything else in the off-season.

The other boy went into radio and he gave it up because the air quality in the studio caused visual distortion which, as he described, made the words of a newscast he was reading dance on the page.

A friend of mine, a technical producer, was interested in his coming out to Vancouver to audition for work with CBC Television but nothing came of it because my son knew that he could not manage. So he left radio and now works in the construction trade where he is also being exposed to highly neurotoxic chemicals.

Thank you for your attention.

Ms. Junor: — Thank you very much. Are there any questions from the committee?

Mr. Thomson: — I simply want to thank Ms. Laporte for coming today and sharing her story with us, and obviously bringing to our attention an important issue. I thank you very much for taking your time, and I want to wish you well in your future health.

Hon. Mr. Melenchuk: — Just one quick question. In terms of your ability to highlight the tragedy associated with multiple chemical sensitivities, in respect of the hearings that we're participating on in terms of the Fyke report, do you have a suggestion to make in terms of what you might like to see in Saskatchewan? Or perhaps . . . one of the recommendations from Fyke was to look at very specialized centres on a regional basis, as a recommendation.

Would you be in favour or support of having an environmental disease centre, say in Western Canada, that would allow for these types of diseases to be investigated and treated on an ongoing basis?

Hon. Mr. Belanger: —Just one question that I have in terms of the challenges that you spoke about and the fact that this diagnosis is not prevalent out there. Do you have any idea as to how many people out there that would suffer from the same conditions as you? And is there any kind of support group or . . .

Ms. Laporte: — There is a group of physicians located in Ontario and they call themselves the Society of Environmental Medicine. There is also a support group based out of Ontario as well, and I'm not affiliated with them because for me, it's really all I can do to just get through one day to another.

But from the reading that I've done in popular magazines, these people I think say that now there's four and a half million Canadians afflicted with this problem. So that's quite a few.

The Chair: — Thank you very much on behalf of the committee, and we do thank you for coming and we do wish you well.

Ms. Laporte: — Thank you.

The Chair: — Rev. Lalonde, if you'd like to come and take a chair. We've passed out your presentation, thank you very much. I'll just reintroduce ourselves. I'm Judy Junor, Chair of the Standing Committee on Health Care; the Vice-Chair is Dr. Melenchuk; Andrew Thomson; Warren McCall; Buckley Belanger; Brenda Bakken; Bill Boyd; and Rod Gantefoer.

The committee is a committee of the Legislative Assembly. It's an all-party committee and it's tasked to report by the end of August — August 30 — back to the Legislative Assembly. And our direction from the Assembly was to receive and report on responses to the Fyke Commission.

And we've been giving people . . . they've had . . . we've had 30-minute presentations and in that 30 minutes are included time for questions from the committee. So if you would like to introduce yourself and then begin your presentation.

Rev. Lalonde: — Thank you. My name is Albert Lalonde. I speak to you as a sufferer of multiple chemical sensitivities. Since lunch time is almost upon us, I will try and follow the advice given to . . . wise advice given to some speakers which is be clear, be brief, and be gone.

Mr. Chairman, ladies and gentleman of the committee, I wish to express my gratitude to the committee members and all who have worked to make these hearings possible. Your efforts are much appreciated. It's not by accident that I follow Mrs. Laporte as presenter. I was present when she spoke to the Clerk of the Committee to make arrangements to be a presenter. She suggested to the Clerk that I also be allowed to speak.

When I spoke to the Clerk, he asked me whether I would simply be repeating what Mrs. Laporte said. I assured him I would be making my own unique contribution.

Now let me introduce myself. My name is Albert Lalonde. I'm a Roman Catholic priest. I worked for 11 years in journalism. My office was in the same building as a print shop. At the end of 11 years, although I did not know it at the time, I had in fact developed a full-blown case of multiple chemical sensitivities, abbreviated as MCS.

I hold degrees from three universities: one in Canada, one in the United States, and one in Europe. I know five languages well and have a rudimentary understanding of two more. Hopefully this will lend credibility to my words even though some of them may seem hard to swallow.

My experience of multiple chemical sensitivities and neurotoxicity involves hardships finding medical people who are knowledgeable about this condition. For example, at one point I needed to see a clinical neurotoxicologist. For over three months I tried to find one in Canada.

I wrote to all the colleges of physicians and surgeons, inquired of two neurological departments of our most prestigious hospitals, and two departments of toxicology. None of them could direct me to a clinical neurotoxicologist in Canada. I had to travel to the United States to find one.

His diagnosis was that I sustained permanent damage to my nervous system because of exposure to neurotoxic substances. The health care system did not pay for me to go to the United States to consult this clinical neurotoxicologist. I had to pay that myself.

As a person with MCS I have learned that appropriate housing is extremely difficult to find. In 1994 I was pastor of the mission at Cumberland House, Saskatchewan. The rectory there had been in need of renovation for a long time. I had the renovations done and had warned the contractors to avoid the use of building materials that contained neurotoxic substances, for example, formaldehyde. They did not respect my request mainly because the commonly used building materials all contain things like styrene — the linoleum —, formaldehyde in K4 particle board, and particle board in the kitchen cabinets. As a result, the air quality was so bad I could no longer live in the rectory. I had to move out.

Through her contacts in the occupational health division of the Department of Labour, Mrs. Laporte was able to monitor the air quality in the rectory for solvent-based substances that are highly neurotoxic, for example formaldehyde. The tests confirmed the presence of formaldehyde and volatile organic compounds at levels up to six times above the level where corrective action was called for.

This testing was done through the Department of Labour. How should anyone who has indoor air problems in his residence in Saskatchewan know that he must approach the Department of Labour? Why is it that such a service is not available through the Department of Health? What's wrong with the system?

In 1997 I requested Dr. Stephen Barron of Vancouver to write me a letter explaining my need for special housing. I chose Dr. Barron because I had learned that he had worked with Canada Mortgage and Housing on their project of Housing for the Environmentally Sensitive. June 30 of 1997 he wrote me an eight-page letter in which he reviewed my medical history, accurately described a multiple chemical sensitivity disorder, and applied that to my housing needs.

The last paragraph of his letter reads:

> I have enclosed a bibliography for your review. I have also enclosed a copy of a report I did for CMHC in 1990. While the medical community has not become much better informed since 1990, Canada Mortgage and Housing has done a lot of research and has produced a lot of very good publications that can be used by patients with MCS as well as by builders who need advice on clean air housing construction.

His bibliography ran to three pages. Why are our medical people ignorant of these things? Why did I have to approach someone in British Columbia to find this out? What's wrong with the system?

When it comes to problems with the system, we should consider this. In the October/November 1997 issue, beginning on page 7, *Health Naturally* published an interview with Dr. Michèle Brill-Edwards. They introduced the interview by telling us about Dr. Edwards:

> Michèle Brill-Edwards was the senior physician responsible for prescription drug approval for the Health Protection Branch from 1988 to 1992. Over the years, she became aware of repeated abuses and illegality within the drug regulatory process, jeopardizing lives to bow to political and industry pressure. In January of 1996, she resigned to publicly protest the deficiencies of Canada's drug safety systems.

I will read you some excerpts from that interview.

Speaking of the reasons for Dr. Brill-Edwards's resignation, the interviewer asked, quote:

> I believe it was the case of the drug Nifedipine that particularly disturbed you?

Answer:

> Nifedipine was the last straw in a series of problematic decisions. Nifedipine is a heart medication used for high blood pressure and angina. It comes in several forms. The earliest form was what we call "short-acting" Nifedipine and was marketed in 1982. In the late '80s and early '90s, more and more evidence began to accrue showing that Nifedipine, rather than extending life, was perhaps shortening life, as compared to other treatments.
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> That evidence was very important because Nifedipine was one of the most widely used heart drugs worldwide. It is the duty both of the manufacturer and the Department of Health to alert the public and physicians if the evidence shows cause for concern. Our department and other regulators around the world tended to ignore that information. When it finally came to a head publicly, we adopted an attitude of delay. Instead of investigating vigorously, we took very slow half-measures to try to deal with the situation.
>
> Finally, in September 1995, we convened a committee that was in essence a travesty. It was a committee of experts who had appeared to have already judged the situation, some of whom had very clear-cut conflicts of interest: They had close ties to the pharmaceutical firms making Nifedipine. And this committee was kept entirely behind closed doors. The so-called expert physicians who were examining Nifedipine were not conducting themselves in a scientifically acceptable fashion. What I saw was the bias against finding anything really wrong with the product by using supporting arguments that were patently inaccurate. It was only after I had resigned that I became aware of the actual extent of interaction between the companies and the supposed unbiased experts.

Did you notice what was being said? Number one, with regard to Nifedipine, pharmaceutical firms were able to co-opt some members of the regulatory committee, influencing them not to rule against the drug. Number two, the committee worked behind closed doors. That is, there was an effective control of information.

In answering a further question, she had this to say, quote:

> . . . On July 5 there was a front-page story in *The Globe and Mail* about Nifedipine. The committee reviewed the decision about the drug and despite all the evidence miraculously concluded there should be no change in its status and all forms of Nifedipine would be left on the market. This is despite a new analysis that came out from a group at Harvard University last year saying that short-acting Nifedipine is more likely to cause heart attacks and death in people with angina.
>
> The department and its supposed advisors appear wilfully blind to the risks of one of the most widely used prescription drugs — a multi-billion dollar market worldwide. In Ontario alone in each year of the early '90s, the government paid out over $30 million of taxpayers' money just for Nifedipine. This is for seniors and people on low incomes. The cost didn't include those taking the drug while in hospital or people on drug plans or those who pay for their own drugs.

Question:

> Because of your integrity and courage going public, have the drug companies tried to buy you off or keep you quiet in any way?

Answer:

> I think the earlier attempts to, quote, hire my silence, were less than successful. I don't anticipate that there will be any further attempts at this stage. There comes a point when it becomes quite clear that you're not going to be silenced.

Question:

> More than one drug company?

Answer:

> Yes. They would argue that they were simply hiring someone's expertise.

Question:

> Did they lean on you heavily when you didn't express interest in being bought off?

Answer:

> The overt approaches are always very subtle, sophisticated. They are undertaken with exquisite conduct. It is a very sophisticated, astute, capable industry. . .

Question:

> Why does the health protection branch ignore information about drug risk or take insufficient time to study the potential risk?

Answer:

> The current business climate has resulted in a political policy called deregulation that in essence holds that the marketplace should function with as little interference from government as possible. Since the late '70s, there has been a diminished political will to regulate many sectors of the economy: transport, banking, drugs. This allows the business sector to conduct their business unimpeded. The philosophy is that economic progress takes precedence over human life, although it is never put that bluntly.
>
> Starting in the 1980s, I was actually involved in setting up a program that was ordered by Mulroney's cabinet under the

> Stein committee that wanted new systems for speeding up drug approvals. So it's not speculation to say that industry pressure on government has resulted in these policies and new procedures to speed up . . . policies and new procedures to speed up drug approvals. It's a matter of record.

The interview continues. Question:

> So you are relying on the manufacturer, who has these vast profits at stake, to give you accurate and honest information.

Answer:

> Yes, they are required to be honest by law but under the old regulatory framework we took the time and applied the expertise to be sure that the research information/evidence backed up the claims of usefulness and safety made by the manufacturer. That capacity has been largely diminished over the last decade or so.
>
> In addition, we had our own scientists in the drug research labs who could assist us with questions of special interpretation of testing systems and standards of drugs. Those labs have just been closed along with the food research labs. The food research labs are Canada's early warning system for identifying and investigating new food hazards like lead in raisins, PCBs in milk cartons and the toxic mussel deaths of 1987. With these labs, we lose a major foundation of our independent expertise as regulators. The (health protection branch) is becoming more and more the servant of the pharmaceutical industry. The senior officials are on record instructing the staff that (health protection branch's) client is the industry, that is, those who pay the cost recovery fees.

Where do the doctors fit into the system? The next question addresses that.

Question:

> I understand that individual doctors get their information on drugs from this CPS (Compendium of Pharmaceuticals and Specialties), which in turn, is based on information from Health Canada. Are doctors getting what they need from the CPS to prescribe drugs safely or are there big gaps in the information?

Answer:

> In essence, the CPS is the linkage between everyday medical practice and the Food and Drugs Act. The information contained in the CPS is in fact drawn from the information provided by the manufacturer and approved by Health Canada. Most physicians consult the CPS on a daily and weekly basis as they work. So, when a drug is mischaracterized as safer than it really is, it results in physicians making decisions that are less safe than they could be, leading to trouble that was preventable.
>
> The public outcry over Nifedipine came in the spring of 1995. That fall the department held the famous secret advisory meeting that was flawed by conflict of interest. By January of 1996 the department issued the "Dear Doctor" letter warning physicians of problems with Nifedipine.
>
> By 1997, when the new CPS came out, there was nothing to reflect what was in the warning letter a full year earlier. So the department was in essence handing the manufacturers of Nifedipine a gift. They sent out a letter with a garbled, lukewarm warning, so that if the physician continued to use the product and any patient sued, both the department and the companies could say, "Well, there was a warning letter." But they didn't put anything in the official product monograph.

Question:

> This puts the doctors in a very difficult position.

Answer:

> The average doctor has no way of knowing that the approval systems that were reliable in the past do not exist today. It is very much as though you were living in a home that had a security system and someone came and quietly disabled the system without telling you so that you think you are protected when you in fact are not.
>
> Many physicians will say, "Well I'm sure if there were problems someone would speak up." Very qualified physicians in the research community have spoken up but the weight of government and industry combined crushed any kind of warning signals from the profession. Family doctors are caught in the middle. They don't have any way of knowing what the data really shows.

The interview goes on to point out that natural products are the emerging market of the '90s, but that regulatory restrictions are sometimes being applied to them in an abrupt and vigorous fashion, while these same regulations are laxly applied to the pharmaceutical products.

Dr. Brill-Edwards tells us:

> The government's actions just show the hollowness of their position — attacking things like garlic while continuing to approve a glaringly harmful drug like short-acting Nifedipine. The only theme in common is that the actions of the department benefit the multinational companies.

If what she says is true, it means the most vulnerable sector of our society, our sick, are being manipulated by deception and exploited by greed. Where is there accountability?

In this kind of system, it is governments that are accountable to the large companies. In the eyes of these companies sick people are useful consumers of their products. Since the bottom line is the profit margin, sacrificing a few human lives along the way is just the cost of doing business.

Unless governments accountable to the people take back control, the human lost . . . the human cost will simply grow higher and higher.

Commenting on the Krever inquiry Dr. Brill-Edwards said:

> . . . I think the Canadian public can't comprehend all of the scandalous information that came out of the Krever inquiry — that tainted product was sent to the Hospital for Sick Children — 98 vials of untreated product that we knew had a much higher likelihood of being contaminated with HIV than the safely treated product. And the safely treated product was available, there on the shelf. Ninety-eight vials of untreated product went out that day before the deadline to stop using it.

In response to the question:

> Has the blood supply really been cleaned up?

She replied:

> The so-called new blood system is a sham — just the old system dressed up with new shoes. Nothing has changed. When we look at blood we have the scandals of the '80s with HIV and Hepatitis C, but it doesn't stop there. We recently learned in April of this year that the bureau of biologics is quite aware that there is a serious problem of bacterial contamination of blood products called platelets. Platelets are a small component of blood that help blood to clot and they are used generally on people who are very ill. People with bleeding disorders that are in crises, burn patients, and patients with very serious infections. These people can ill afford to have live bacteria directly injected into their veins by virtue of a contaminated bag of platelets. But no warning has been sent out.
>
> With blood we have past evidence of lax regulation, current ongoing evidence of lax regulation, and failure of the department to ensure that the manufacturer makes known to physicians the dangers in the product . . .
>
> Where in the system is there accountability for this? Who's minding the store? Where does that leave the blood used in our hospitals?

I make no bones about the fact that because of my health problems I feel I have been marginalized and ignored by the system. A recent incident impressed that upon me in a very concrete way.

On January 5 of this year, I was injured while trying to change the tire on a friend's truck. The handle of the Jack-All I was using struck me on the head, smashed my glasses, cut both sides of the bridge of my nose, broke my nose, and smashed my left thumb, breaking it in three places.

I will spare you the details of my six-hour wait in the emergency at the General Hospital before I was seen by a doctor and had the thumb X-rayed. The next day, it was put into temporary cast. Although it was evident that the bones needed to be drawn into line, the plastic surgeon did not pin the bones.

When I went in to get a permanent cast, Mrs. Laporte came with me. It is fortunate that she did because when I'm exposed to chemicals in a hospital environment, my mental processes seize up and I become inarticulate. I cannot find the words I need to express myself, not in any of my five languages.

She tried to explain to the hospital personnel that I could not have a fibreglass cast because of the chemicals it out-gases. They would not listen to her attempts to explain the needs of the chemically sensitive. When she refused to be intimidated, they called the police and had her thrown out of the hospital. For me, it was a concrete example of the system considering that people with chemical sensitivity are nothing more than troublemakers and people with psychological problems.

Am I merely reflecting the unbalanced views of a select few? Apparently not. In the March, 2001 issue of *Alive* magazine, Judith Spence, the CEO (chief executive officer) for the Environmental Illness Society of Canada, claims that there are four and a half million Canadians with environmental illness. That's almost one in seven. Even if you halve or quarter that, you're looking at a lot of people.

In the winter, 1990 issue of *The Human Ecologist*, there appeared an article entitled "Neurotoxicity and Environmental Illness" by Dr. Raymond Singer, an epidemiologist, neurotoxicologist, and Ph.D psychologist. It contained this interesting passage, quote:

> The downfall of the Roman Empire has been attributed to lead poisoning from a variety of sources: water pollution due to lead plumbing; possible food contamination from lead plates; and wine contaminated from vessels used for growing and storing.

What are we then to say about our day and age?

In the book *Our Stolen Future*, we read:

> Around the world, one hundred thousand synthetic chemicals are now on the market. Each year one thousand new substances are introduced, most of them without adequate testing and review. At best, existing testing facilities worldwide can test only five hundred substances a year. In reality, only a fraction of this number actually do get tested.
>
> The world market in pesticides amounted to 5 billion pounds in 1989 and included sixteen hundred chemicals. Worldwide use is still increasing. Pesticides are a special class of chemicals in that they are biologically active by design and intentionally dispersed into the environment.

In a video produced by the World Wildlife Fund and available in the Regina Public Library, Theo Colborn states that as low as two parts per trillion in a single hit of a certain biologically active toxic chemicals at a critical time of development of the child in the womb is enough to wire the brain wrong.

For some of you this may seem overwhelming. It need not be. It's not that we cannot deal with these problems; it's that our resources at present are, to some extent, being misapplied. Unless the right questions are asked, we will never arrive at the right answers. As long as we persist in sweeping under the rug the whole question of the impact of our polluted environment on people's health, misdiagnosis and misuse of medications will be the order of the day.

As frustration mounts for everyone involved, the confusion and anger surrounding our present health system will continue to grow.

As I conclude, let me say this: I do not ask you to believe anything I say. I do challenge you to consider the issues raised and investigate them for yourselves.

One last observation — already in 1985 the Thomson commission set up by the Ontario Ministry of Health pointed to the fact that there was a preference to accept from a doctor practicing conventional medicine the opinion that people who claimed that they had become ill from the environment were, quote, "mentally disabled," rather than except the opinion of a clinical ecologist that these people were truly ill.

At the beginning of my presentation I mentioned consulting a clinical neurotoxicologist in the United States. It was my good fortune that this man was also a Ph.D. (Doctor of Philosophy) psychologist. I told him my superiors who are paying for my consultation with you think I'm on a hypochondriac kick to get attention. In your testing of me, I want you to throw the book at me as far as malingering is concerned.

And he did. Of the battery of 25 tests or so he put me through, 10 of them were to determine whether I was malingering. The tests revealed no sign whatever of malingering on my part. So I can say that if anyone thinks I'm crazy, I have my papers to prove that I'm not. Do you have yours?

Thank you for listening.

The Chair: — Thank you, Rev. Lalonde. On behalf of the committee thank you for coming today. And now is there any questions from the committee?

Hon. Mr. Melenchuk: — In terms of both the presentations we've heard this morning, it's certainly thought provoking. But in terms of recommendations with regard to what you would like to see, you've highlighted a few areas. I think both of the presenters today talked about an increased emphasis on the understanding of multiple chemical sensitivities within the undergraduate health sciences curriculum in this province. I think you would both agree with that. Also the need with regard to the availability of multiple chemical sensitivity specialists, neurotoxicologists, and environmental disease specialists perhaps within Western Canada.

A lot of your presentation was related to perhaps more stringent federal regulations with regard to interaction of the pharmaceutical industry and the health sciences within Canada. And the approach generally with regard to environmental concerns not only from pharmaceuticals but producers of toxic chemicals, and greater I guess public education and knowledge with regard to the usage of these and perhaps more stringent guidelines or regulations as well.

Would that be a fair summary of what you were attempting . . .

Rev. Lalonde: — Certainly. I would . . . Yes, I would go along with that.

Hon. Mr. Melenchuk: — Thank you.

The Chair: — Thank you very much. There's no other questions. Then we again thank you for your presentation, and I'll entertain a motion now to adjourn. We'll be adjourned until next Tuesday, the 10th, at 10 o'clock.

The committee adjourned at 12:02.