

Legislative Assembly of Alberta The 27th Legislature First Session

Standing Committee on Health

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Alberta Disabilities Forum Melita Avdagovska Michelle Kristinson Bev Matthiessen Tamina Selig	HE-139
Glenrose Rehabilitation Hospital Foundation Don Cranston, QC Ted Purcell	HE-142
Alberta Provincial Respiratory Strategy Dean Befus Bob Cowie Gina Ibach Brent Winston	HE-146
Campaign for a Smoke-Free Alberta Fred Ashbury Les Hagen	HE-149

8:30 a.m.

Tuesday, November 18, 2008

[Mr. Horne in the chair]

The Chair: Good morning, ladies and gentlemen. I'd like to welcome you to this meeting of the Standing Committee on Health. We have a number of presenters this morning, and I'll talk about the process in just a minute. Before we begin, I'd like to give the members and staff seated at the table an opportunity to introduce themselves, and we'll come back to our guests subsequent to that. So if we could start with the deputy chair.

Ms Pastoor: Bridget Pastoor, Lethbridge-East.

Dr. Sherman: Raj Sherman, Edmonton-Meadowlark.

Mr. Denis: Jonathan Denis, Calgary-Egmont.

Mr. Vandermeer: Tony Vandermeer, Edmonton-Beverly-Clareview.

Mr. Olson: Good morning. Verlyn Olson, Wetaskiwin-Camrose.

Dr. Massolin: Good morning. Philip Massolin, committee research co-ordinator, Legislative Assembly Office.

Mr. Dallas: Good morning. Cal Dallas, Red Deer-South.

Ms Norton: Erin Norton, committee clerk.

The Chair: I'm Fred Horne, MLA for Edmonton-Rutherford and chair of the committee.

A few housekeeping matters before we begin. The members will be well versed in this. If you're a presenter this morning and are seated at the table, I'd just ask you to please keep your BlackBerry preferably off the table in front of you. The microphones pick up the interference from it, and it can make it difficult for what we fondly refer to as our listening audience. The other thing I should mention is that the proceedings of the committee are not only recorded in *Hansard*; they are broadcast – audiostreamed I believe is the term – on the Internet, so we try to make a point of minimizing any electronic interference.

We have a number of groups that are going to be presenting today. I'll apologize a bit in advance. The House is in session, and we will have some members that need to leave a little early or that, perhaps, come in partway through a presentation, so we apologize in advance. It's just the nature of the particular time that we're in here. We're down to the last few weeks of this session of the Legislature.

I'd just like to introduce Rachel Notley, who has joined us, MLA for Edmonton-Strathcona.

Ms Notley: Good morning.

The Chair: Good morning.

And Melanie Friesacher, seated at the far end, is with the Legislative Assembly Office.

For those of you that are here this morning, thank you very much for coming. The members have been looking forward to these two meetings for some time. I just want to say for the record that this meeting is constituted as a public meeting under the standing orders of the Legislative Assembly. That allows standing committees of the Legislature such as this one to hear from groups who wish to present to the committee on virtually any topic that is of interest to the committee and falls within its three portfolio areas, which include Health and Wellness, Children and Youth Services, and Seniors and Community Supports. Those are the three portfolios that our committee covers.

We have laid out a process, which I think the clerk has probably briefed you quite well on in advance. We have approximately 30 minutes per group that is presenting. We've asked that that be divided between up to 15 minutes for a formal presentation, and then we'd like to leave at least 15 minutes for the committee members to ask some questions. Then we'll be moving on to the next group. We will likely have the group following you seated in the gallery behind, so there will be a bit of movement at the end of the 30 minutes. We have until 11 o'clock this morning. So I apologize for the pace, but it was a toss-up between a lively paced morning or not hearing from as many groups as expressed an interest in coming.

Without anything further, then, we have a couple of quick matters of business, and I'll just ask for the co-operation of members. Can I have a motion, please, to approve the agenda as circulated? Mr. Dallas. Any discussion? Those in favour? Opposed? That's carried. Thank you.

The third item: the adoption of the minutes of our meeting of November 3, 2008. May I have a motion to accept the minutes as circulated, please? Mr. Olson. Any discussion or corrections? Those in favour? Opposed? Thank you very much.

We'll move, then, to item 4, and the first presentation this morning is from the Alberta Association of Services for Children and Families. I'm going to ask one member of the delegation to just introduce the group. It's not quite clear to me here who's going to be doing the speaking, so I'll let you apprise us of that. Please proceed.

Alberta Association of Services for Children and Families

Ms Kilgallon: Good morning. My name is Patty Kilgallon, and I'm the president of the Alberta Association of Services for Children and Families. On my left is Danica Frazer, and she is president-elect of the association; on my right, Nancy Laird, who is a board member with an agency, Hull Child and Family Services, and on the board of the Alberta Association of Services for Children and Families; and Susan Gardiner, on the far right, is on our strategic initiatives committee and also an executive at a Calgary agency.

Thank you for giving the Alberta Association of Services for Children and Families the opportunity to meet with you today in order to discuss the need to build strong and sustainable communities through strong and healthy agencies, who are essential to Alberta's vulnerable children and families. The association is a membership association formed in 1967 representing child- and family-serving agencies in an effort to promote attitudes, practices, and conditions that contribute to quality program service delivery. The association represents 139 members, approximately 7,000 employees. Most importantly, we represent agencies who serve 80,000 of Alberta's vulnerable children and families.

It is vital that services that support these children are strong. Some of these children are children who were abused by those whom they trust, children who are in the care of the Alberta government through foster homes and group care, teenagers who run away and get involved in drugs, high-risk new moms who are learning to parent newborns, and children with severe learning difficulties.

I know that we have provided you with a document today, and we hope that we have demonstrated through this document that our requests and solutions have been put together with a great deal of thought to enable a solution to a historical problem that has made it difficult to sustain essential services for these children. We have every confidence that each of you is invested in our sector. We can all agree that funded agencies represent essential services to complex children and families who require skilled professionals to ensure their success. We know that you are all aware that all staff working in the funded agencies are your agents serving those most in need.

As you've had an opportunity to review the document, I'll take a moment to highlight our concerns and the required solutions. After this review we'd like to engage in a dialogue with you to discuss the uniqueness of the situation relative to the essential services we provide.

Our greatest concern and issue that we are bringing forward is that we need sustainable and predictable funding to recruit and retain qualified staff to care for Alberta's most vulnerable children and families. Agencies are increasingly unable to attract and retain qualified employees due to the low compensation they are able to offer relative to other sectors. In 2007 we reported having experienced a 20 per cent turnover rate. In 2008 the turnover rate rose to an alarming 40 per cent, leaving programs with increasingly inexperienced staff to serve complex children and their families.

In your document on page 7 is a chart that looks like this. It's entitled Wage Comparison 2008. It demonstrates a wage gap range of 33.5 to 38.6 per cent, the difference between salaries that agencies are able to pay staff with comparable education to those in comparable positions in the public sector. This results in agencies training staff and quickly losing them to other sectors that pay much more. Our staff leave with great regret but feel they have no choice given the economic climate and their need to earn a sustainable income.

The staffing pressures we are experiencing are the result of historical insufficient funding for staff compensation, which is compounded by sporadic and targeted increases. This has resulted in significant disparities. Again, there's another chart, which is on page 8, and it looks like this. It's called Salary Adjustment Experience by Alberta Agencies 1985–2008. As you can see by this graph, the sector experienced consistent gaps in funding for wage increases, causing long-term problems. You'll see on that chart the gaps where there were no increases and the number of years in between that have caused this issue that we're talking about today. It indicates a 52.8 per cent increase over 23 years as compared to a national consumer price index of 78.84 per cent. Agencies have fallen below this by 26 per cent. We are experiencing wage deficits caused by an historical gap.

8:40

Agencies do require sustainable and predictable funding for wages and benefits in order to recruit and retain qualified staff to run essential programs and services. Funded agencies have taken steps over the past years to resolve the ongoing issues they face. This has been done through fundraising, increased volunteerism, collaborating with agencies and the community, updating employment practices, and actively working with the ministry and local child and family services authorities to ensure that essential services to children and families are available.

The Ministry of Children and Youth Services has taken steps as well, and we'd like to take a moment to recognize Minister Tarchuk and the government of Alberta for their efforts and recent important steps to alleviate aspects of funded agencies' unique human resource situation. We know that Minister Tarchuk is supportive of working toward solutions to strengthen service delivery to Alberta's children. As of today concerns about sustainable services in the sector are very real. The association urges the government through the Ministry of Children and Youth Services to take action to alleviate the current situation. We have demonstrated in the document three solutions. The first one and the most important one, that we know needs to be dealt with over a period of time, is to reduce the historical gap by funding a 30 per cent extraordinary adjustment to contracts. This would be distributed over a three-year time period with a 10 per cent annual extraordinary compensation per year for three years. The overall cost of this would be approximately \$22 million a year.

Secondly, we can't forget, as we're doing extraordinary adjustments, to address annual inflation as demonstrated by the ministry in 2008 when a 5 per cent increase for 2009 was announced in the spring of 2008. We need the ability to have such predictable annual funding to sustain needed programs. What we're saying is that we need to have the 10 per cent over three years and, on top of that, make sure that we have inflationary increases addressed so that we don't end up with a longer period of time where the gaps just continue to persist.

Lastly, we have a relationship with the Children and Youth Services ministry, and we need to continue that relationship to really look at methods of service delivery leading to positive outcomes for vulnerable children and families. This is an invaluable relationship, and the government has made huge steps toward making sure that programs are being looked at regularly and that there is an advisory capacity for many agencies across Alberta to have input and help lead the new charge.

Thank you very much. My colleagues and I would like to address and discuss the issues with you and are prepared to answer questions. I also had distributed this morning a document that was prepared out of Calgary by United Way and the Calgary Chamber of Voluntary Organizations, and this is just a supplement today for your benefit, to be able to have something handy that has come out now that speaks about the workforce crunch in nonprofits in a myths and reality sort of way and supports what we're saying today.

Thank you very much.

The Chair: Thank you very much for your presentation. I have a speakers list started. Mr. Fawcett, please.

Mr. Fawcett: Thank you, Mr. Chair. I have a few questions, but before I get to them, I have one basic question, and maybe it's because I'm new to this. How exactly are your organizations and agencies funded? What is the method? Is it on a per-case basis? I think that's important for me to understand before I ask my next set of questions.

Ms Kilgallon: Agencies are funded through the local child and family services authorities. There are contracts that all agencies have with each authority, and then there could be a contract to deliver a service. You might get quarterly funding, or you might have a fee-for-service arrangement. Both are common.

The Chair: Anything further, Mr. Fawcett?

Mr. Fawcett: No, but I'll go back on the list.

The Chair: Okay. I have Ms Notley next.

Ms Notley: I have a whole schwack of questions, but I guess we'll have to sort of take turns.

The Chair: Yeah. I think what we'll try to do is keep it to one main and one supplementary question if we can.

Ms Notley: I guess that maybe what I'd like is just to sort of get an overview. You mentioned you have, I think – is it correct? – about 7,000 employees in your organizations collectively. How does that relate to the number of employees directly employed by the government to provide similar services? What is sort of the general number in the direct employ of government?

Then I have one supplementary.

Ms Kilgallon: I'm sorry; I don't have that number.

Ms Notley: Okay. Then you may or may not be able to answer the next question. I'm wondering if you can tell me how Alberta compares to other jurisdictions with respect to the degree to which these kinds of services are provided through the nonprofit sector, through agencies like yours versus other jurisdictions. Is it the same, more, less? Maybe you don't know.

Ms Kilgallon: Will you field that, Susan?

Ms Gardiner: Okay. I think it depends. In Ontario, for example, where there are children's aid societies, all those services are provided by the community, including the child protection arm. In other jurisdictions it's more a combination, like we have in Alberta.

Ms Notley: Okay.

The Chair: Thank you.

Mr. Olson: I also have lots of questions. First, I want to say thank you for coming. Also, I want to say that your members are very effective at getting your message out. I've certainly heard from, you know, organizations within my constituency addressing these same questions.

I have, like I say, a bunch of questions. One thing that strikes me is in making comparisons. How easy is it to compare the actual workload and the level of responsibility and so on that agency workers perform compared to government workers? I'm not for a minute suggesting that that would justify a big gap. I'm just wondering how the comparison is made and if you feel confident in those numbers.

Ms Laird: I'll take a run at that, sitting as a director of one of the larger agencies. Workload in terms of hours is one thing. I think that workload in terms of risk is another. If you think about the risk, when you're feeling understaffed and potentially skill minimal - in other words, you've lost your expertise, and you've lost your capacity - when you're dealing with high-risk children, from my point of view the risk of the work at the delivery level is far greater as an impact on sustainability, ability to stay the course, emotional concerns for the staff. In no way do I suggest that the government staff don't have similar ones, but they're at a different level. You're not directly in front of a very challenging client. You're one step removed, looking at case files. Now, that can also be very stressful, but when you have that client reality 24/7 - safety, understaffed that creates a whole new mecca, and that's the burnout rate we're experiencing. So from a burnout rate point of view I would say that the agencies have the greater risk of that continuing and accelerating unless we put some value on that risk.

Ms Gardiner: We tried, for comparison's sake, going back to page 7, to pick positions where there would be a direct comparison. You notice that in that chart we're talking about child and youth care

workers, which would be the bulk of our front-line delivery people. There are comparable government positions there, and you see that 34 per cent difference in salary.

Mr. Olson: Thank you.

This is just another question. It's not necessarily a supplemental, so perhaps it would be fairer if I let you move on, Mr. Chair.

The Chair: Okay. We'll try and make our way around the table and then come back.

Ms Pastoor, please.

8:50

Ms Pastoor: Yes. Thank you very much for coming this morning. Of the agencies, are they all nonprofit, or are there agencies for profit?

Ms Kilgallon: There are some agencies for profit. The bulk of them are nonprofit.

Ms Pastoor: Okay. Then my other question. Is the money that's being allocated – I see that there's 5 per cent for the 2009-2010 budget – being allocated for staffing, for wages, and are we sure that it actually makes it through to the front-line workers?

Ms Gardiner: Yes, because there are good controls on that. We have reporting data back to the government to ensure where that money is applied.

Ms Pastoor: Would that information apply to both nonprofit and profit, or do you know?

Ms Kilgallon: Yes.

Ms Gardiner: Yes.

The Chair: Thank you.

Mr. Dallas, please.

Mr. Dallas: Thanks very much. Thanks for being here this morning. The wage gap, I think, we recognize. We see it, and we acknowledge that it's a major issue. The complexity of that gap and how it impacts other segments of our society and the need to provide services in those areas as well – and I'll use seniors and the elderly as a complementary example – make the challenge exasperating.

So back to the area where my colleague was. Your third solution talks about working in collaboration with the ministry on service delivery. I guess I'm wondering if you can give us some examples of areas where efficiencies can be realized so that perhaps we can find a way to free up some of these dollars and also speak to the reality that we have, that many agencies entail administrative costs on an organizational basis and what types of energy the association is applying in terms of looking at opportunities to consolidate administrative costs and the governance side of these operations.

Ms Kilgallon: That's a question that I think we deal with a lot because there are many contracted agencies. In the past year there was an admin efficiency study that was done by the Alberta Association of Services for Children and funded by the Ministry of Children and Youth Services. We're right now taking a look at some of the results of that to make some recommendations to move forward on at the end of this month. We've been working with the ministry on issues of: how do agencies partner more? How do agencies merge? How do we support them in those kinds of opportunities? You know, is it all about mergers, or is it sometimes better to leave an agency stand-alone if they're doing a tremendous job and there isn't duplication in any way? So to make sure that that is respected and sustained.

The other piece of it is that there are about 11 agencies that the ministry has invited to a committee called new business relationships. That came out of a meeting that the ministry and agencies sat in together in May and are now looking towards: how do we do service to children differently? How does that impact the model that agencies are presently utilizing? I think there is a lot of work that is right now being exercised toward exactly what you're talking about in terms of how many agencies, how efficient we can be, and do we know that. We have a system that is effective and working, you know, and I think that it's under a constant microscope at this point in time and being worked on jointly.

Ms Laird: If I can make a supplemental comment on that. Speaking as a community volunteer, what you have to understand is that 80 per cent of the budget is salaries, so a 10 per cent saving on those efficiencies is 2 per cent. Okay? You know, a great idea, but let's understand the ratio of impact. If we have a 40 per cent turnover rate, the biggest issue we have is skills. We are short skills. You know, you can play with the efficiency side all you want and feel really good about that. It's not going to change the needs ratio and the skills ratio requirement that this province has.

The concern as a community member when I look at a valuebased economy, which I like to think Alberta is, is that I'm looking at these numbers trying to understand how we got here and how we can recognize that we've got to change this. The price tag is not that great, but the implications are huge if these children find themselves at risk. I respect your question, you know, but as a community volunteer spending your time, giving your time, and always having to face this same question on the ratio of impact to influence, we've got to make sure we understand those ratios. We work at it, and we don't want people to think we're not responsible and that we're not willing to look at doing things in a new way, but the reality of it is that 80 per cent of our delivery cost is salary.

The Chair: Thank you. Okay. I've got Mr. Denis.

Mr. Denis: Thanks. First of all, thank you again for attending to present before our committee today. Just a question regarding the administrative review that's being conducted: when can we expect to see the results of that, and have there been any preliminary findings you could share with us?

Ms Kilgallon: The results of that should occur at the end of November, so very soon we should have that ready. I think that we learned through our admin review. Agencies were surveyed by an independent source, and from that generally it was stated that agencies are very efficient, and another report, that was done about three years ago by Deloitte, by the ministry, also showed that agencies are very efficient. So now the point is: what can we do to support agencies if there are requirements to partner to try to make some differences on that small percentage of administrative fees that we've got in our budgets? You know, is there some cost sharing that we can do? Are there some opportunities for sharing lease space, those kinds of things? We're still working on that, but I think that it's not going to make significant savings.

The Chair: Okay. Thank you.

We're almost all of the way around here. Dr. Sherman, followed by Mr. Vandermeer, please.

Dr. Sherman: Thank you, Mr. Chair. I'd like to thank you all for coming here today as well as for all the wonderful work all your agencies do. Just a question: can you give me an idea of the levels of training from one end to the other and the wage ranges within those levels of training?

Ms Frazer: In terms of training – and I'm going to preface this with: at one point in time – the educational requirements for most agency staff delivering services were either a diploma or a degree in a related field, so child and youth care or social work. Most agencies offer a combination of mandatory training, so those would include some basic training like suicide intervention, first aid, crisis intervention, and, in addition to that, whatever other specialized training staff required. Those are the preferred qualifications. I don't think I would be speaking out of line if I said that at the current time the number of staff in agencies that have the educational requirements has fallen. Most agencies have been able to maintain the mandatory training required for staff, which relates to basic safety and basic delivery of services, but again most agencies at this time are hard-pressed to provide any specialized training for their staff.

Dr. Sherman: In comparing the caseworkers on the government side with the nonprofit sector, is that level of training and experience for the same worker in the nonprofit sector similar to the one on the government side as well?

Ms Frazer: I'm not sure that I want to answer a question on behalf of what the requirements are for government staff, but I'm going to say that I think the required qualifications are similar, yes.

Ms Laird: Can I just add to that? In light of the fact that we find we're losing most of our staff to government and most of our experienced staff, I think that's the trend. In other words, what we lose, the government benefits from. So their whole level might be shrinking, but at least it's not shrinking at the same rate because they're getting our people moving up from a salary gap solution point of view.

9:00

Ms Kilgallon: Our staff have the education, the same training, the same experience because, obviously, government is able to hire them.

The Chair: Thank you.

Mr. Vandermeer.

Mr. Vandermeer: Yeah. I'd like to thank you, too, for coming. I've met with a number of your organizations over the past couple of months, so I'm quite familiar with your situation. One question I'd like to ask regarding a quote in here. It's saying that many are choosing to leave the field entirely. Have you noticed, with our economy calming down, that situation is changing now?

Ms Kilgallon: I think that in some general conversation people are saying that the turnover in the last couple of months seems to have settled a bit, but it really depends on which region you're in, what has occurred previous to those months. But I do think that our staff are economically challenged at this point in time. They continue to

be economically challenged; they continue to be looking for new opportunities; they continue to look for where they can live, which other provinces can they live in and be able to sustain a living wage. So I don't believe that some of the economic situation that we're facing today has hit them as it might have hit a higher earning income bracket.

Mr. Vandermeer: Thank you.

The Chair: Well, thank you very much. I think we've just about exhausted our time, but I want to thank you very much for taking the time to be here today and for the written material that you've provided. It's been very informative. We're going to pause here for about 30 seconds while we change groups. Thank you so much for coming. Much appreciated.

Ms Kilgallon: Thank you very much for the opportunity. It's very much appreciated as well.

The Chair: Well, good morning. I'd like to welcome our second group presenting this morning, the Alberta Disabilities Forum. I am going to sort of dispense, I think, with individual introductions of the committee members just to save a bit of time. I see that we have some name placards put up. I'd like to welcome you. I recognize Bev Matthiessen. Bev, I wonder if you'd like to introduce your colleagues joining you today.

Alberta Disabilities Forum

Ms Matthiessen: Certainly. Thank you very much, and good morning, everyone. My name is Bev Matthiessen, and I'm from the Alberta Committee of Citizens with Disabilities. This is Michelle next to me from the MS Society, and next to her is Tamina from EmployAbilities. We have Melita and Anthony, and they are from the Alberta Disabilities Forum.

Today we are here to present to you on access to medications for Albertans with disabilities. The Alberta Disabilities Forum is a partnership of 42 provincial organizations that came together over 10 years ago to share ideas and to have a united voice on issues of importance to people with disabilities. One of the issues that's of utmost importance is access to medications. There are over 166,000 Albertans with a disability who regularly take medications for one reason or another.

Mrs. Kristinson: While the ADF was aware that there were issues, we thought that it would be wise to dig a little bit deeper into what was happening with this problem, so last spring we commissioned a survey that included individuals living with disabilities and chronic illnesses. We asked them to provide feedback on access to medication. The survey confirmed what we had been hearing, that people were having access issues.

One of the other interesting parts of the survey came back that people were using alternative forms of health care. Some were using it because they weren't able to access a drug that was available on the market but not covered under the formulary. Others were using alternative forms of health care in combination with mainstream medicine.

As you can see by the individual responses, there are many people who are having access issues: either there's a delay in getting the medication or some medications are being denied because of lack of funding. The medications just aren't on the formulary. In the case of someone with a chronic illness or a disability this can have a devastating consequence if they have to wait for a medication, or in the case where they're not provided the medication, it may mean they will experience deterioration in their medical condition. It also may mean that people suffer unnecessarily with symptoms that could be treated with a medication that may not be currently on the formulary.

As you can see on this slide, according to Stats Canada as of 2007 Alberta is still below the national average for drug spending. I think it's important to point out that there are many studies that illustrate that when you reduce or limit access to appropriate medications, you may save money in a particular budget related to pharmaceuticals; however, there are going to be cost increases on the overall health care system. The reason is that if an individual's medical condition is deteriorating or they're experiencing problems with their symptoms, they're going to access health care through outpatient services and in-patient services, so you're going to see that overall cost increase.

Alberta Disabilities Forum is a big advocate that individuals need choice. As human beings we're all different, and we have different requirements. All of us are unique. One drug may benefit one person and be ineffective for another. It is critical that individuals be able to access medications that have been prescribed by their physician based on a medical assessment and based on their unique needs. So many times people will come back to us and say that their doctor recommended a medication but it's not available, so they're using an alternative, and there are lots of problems with that alternative medication.

Timely and fair access is at the heart of the matter for the people that we're representing today. When treatments are denied or delayed, there are significant consequences for this vulnerable population. An example of this is related to MS. Just a brief explanation of MS, just a very brief one. MS affects the central nervous system, so your brain and spinal cord. What happens is that the body attacks itself. Therefore, it attacks the myelin that covers the nerves, so the transmission of messages from your brain to your body are in disconnect. Now, it affects people in the prime of their lives. There are children that are affected, but the average age is 15 to 40. There are approximately 11,000 Albertans that are affected by MS.

9:10

In terms of the drug therapies, there are four disease-modifying therapies that actually alter the course of MS. Prior to these therapies' being developed, we were just treating MS symptomatically. If a symptom appeared, we tried to treat the symptom. These actually alter the course of the disease. Alberta approved these four therapies in October of 1998, and the program has been extremely successful. It's one of the best in the country. It's probably the best in the country. So we're very fortunate in Alberta.

Just a little bit about the therapies. They reduce the frequency and the severity of attacks by 33 per cent, which is just quite dramatic. However, some individuals will have a disease that is more aggressive, and they stop responding to these particular therapies. In that case they need to go to the next line of defence, which is a drug called Tysabri. Tysabri is currently not on the formulary. What this means for individuals is that when their disease starts to become acutely progressive, they don't have an option unless they can afford to pay for the next line of defence. Now, the cost is prohibitive for most people, especially since they're progressing and probably unable to work at this time. In that case an individual will have to face the fact that they're going to continue to progress and potentially face the realities of this devastating disease. Symptoms may include paralysis, cognitive dysfunction, bowel/bladder dysfunction, extreme fatigue, speech/vision problems, and pain. The cost of MS is significant, as outlined in a study at the University of Calgary, yet the majority of the costs are not related to drug therapies. Generally when we think of preventing disease and injury, we think of programs aimed at helping people make better wellness choices, so quit smoking, increase activity, reduce alcohol consumption. We don't really hear a lot about making sure that people are taking the most appropriate medications that aren't causing additional harm.

In the last couple of weeks I've had the opportunity to speak to the clinicians at the Carnat Centre psychiatric rehabilitation program through Alberta Health Services, which is an outpatient program for individuals with schizophrenia and bipolar disorder. Now, these program clinicians were telling me about a drug called Abilify. Abilify is an atypical antipsychotic for the treatment of schizophrenia and is available in Japan, the U.S., and other European countries. Abilify, what sort of makes it different is that it does not have the same side effects as other antipsychotic medications, that include weight gain, diabetes, and abnormal lipids. The medication will not benefit everyone. However, it is an ideal option for individuals at risk of diabetes, high cholesterol, and cardiac problems.

In the absence of options individuals who have serious side effects from medication will not follow their recommended medical regime, which puts them at serious risk. If one was to look forward to the future in terms of cost and providing services for this medication, it would prove substantially less because it would improve adherence to treatment. It does not appear to be associated with major health conditions such as diabetes, that have a tremendous cost impact on the health system.

Ms Matthiessen: Now we're going to talk about cost as a barrier. For people with disabilities who are trying to access the medications that they require, the main barrier is cost. Sometimes physicians will prescribe medications that are not covered by any government of Alberta programs. These medications are very costly, and a person can't afford to purchase them. As a result, the drug is not taken or is not taken as prescribed. What people will often do is reduce the dosage in an attempt to make the drug last longer. Just as a quote from our paper that we've given you, this is from a woman who says: I have been on AISH since 1983; at present I have six prescriptions that are not covered.

Of all provinces Alberta's public/private drug plans were identified as spending the third-lowest amount of money per person among all provinces. Also, statistics suggest that Alberta's public health insurance plans have more rigid approval criteria for drug therapies than most other jurisdictions in Canada. Limited access to proper drug therapy minimizes health benefits to patients and has the potential to impose even greater costs on the health system. If people can access the proper medications for their conditions, then they can be active, healthy, contributing citizens, often getting and keeping a job.

When an individual needs to have a certain medication for a chronic disability such as rheumatoid arthritis, they cannot wait to access the medication because further swelling and damage occur, and the pain that these individuals experience is extremely debilitating. What we heard from our survey is that there are alternative, holistic therapies that can help if a person can access them. These therapies need to be recognized as effective and beneficial and need to be covered by the Alberta health care insurance plan. Alberta Health and Wellness has challenged Albertans to accept responsibility for their own health and take an active role in managing their own care. Expanding coverage of alternative therapies under the Alberta health care insurance plan and Blue Cross will lift a financial barrier and enable many people with disabilities or with chronic illnesses to manage their own care more effectively.

Removing barriers. Many people with disabilities are completely dependent on specific medications to function. We need to make sure the barriers are removed so they can access these medications. People with disabilities want and have the right to work with their health care professionals to find a treatment that works for them. Treatment options like drug therapy or alternative therapies should not be denied because a person cannot afford them.

Mrs. Selig: Okay. We come down to some of the recommendations from the Alberta Disabilities Forum. The first is to increase patient choice and reduce delays and coverage refusals. We would like to see this list include all physician-prescribed medications deemed necessary for persons with disabilities or chronic illnesses. As an example, I know of a person who has MS and is currently using the drug Lyrica, although Sativex is in another category that could be utilized as well to control neuropathic pain. As some of you may know, that pain can be completely debilitating and basically stop a person's ability to function in what we would call normal day-to-day activities. Because she pays for this medication, the disease is controllable to the point where she can function relatively fully with her family and community. Of course, there still are restrictions of having to be in bed early and limiting her amount of reading time, et cetera. Currently these drugs are not part of the Alberta formulary.

We're also seeing physicians often prescribe medications that work better for people with disabilities that can be bought over the counter. The prescribed meds on the Alberta formulary just don't work as well for these particular individuals. By reducing delays in coverage, well-being can be created that will facilitate continued participation, basically, so people can work, play, and participate in Alberta, and that's what Alberta's advantage is all about.

Our second recommendation is to improve education and counsel to persons with disabilities or chronic illnesses about proper usage and medication coverage options. The Canadian Pharmacists Association estimated the underuse, misuse, and overuse of prescription drugs costs Canadians between \$2 billion and \$9 billion. Eliminating this waste in Alberta would mean a savings of \$2 million to \$9 million. Currently there is no common, independent source of drug information readily available to prescribers and patients to assist them in making informed drug decisions. Developing a source of reputable, unbiased information to assist not only people with disabilities but physicians and patients will require government support and the assistance of professional bodies and will aid in informing best practices for the use of pharmaceuticals.

The next recommendation is to have no cap on drug benefits. While we recognize that there are limits on what a health care system can afford, issues of clinical effectiveness and value should be of primary concern in drug evaluations and establishing budgets that relate to people with disabilities and their needs. Clinical studies have shown the savings in drug costs from a cap were offset by increases in the costs of hospitalization and emergency department care. It is key to remember that the effectiveness of a reference-based drug pricing system is ensuring that drugs included in this process are truly a therapeutic equivalent. This would require an evaluation process by a team of experts who engage in a fair and transparent procedure for the benefit of all Albertans, including people with disabilities. Therefore, we recommend that Alberta Health should not implement a strict cap on drug benefits or expenditures.

9:20

As far as economic benefits go, as I've mentioned, the \$2 million to \$9 million that could be saved with proper education on the use, misuse, and overuse of prescription drugs is one. The bottom line is that medication helps people with disabilities become active, supporting them to participate as members of society in our Alberta economy. This also decreases our hospital and emergency costs. From my particular viewpoint working with people with disabilities and getting them back into employment, medication plays a big role, and when there is a stoppage of that medication, there is a direct breakdown in what happens with jobs and their being able to get to work.

In conclusion, greater pharmaceutical consumption leads not just to longer lives but also to a higher quality of life as measured by the number of years people can expect to live without disability health conditions. In general, countries that currently spend the least on pharmaceuticals would see the greatest benefit from an increase in that spending.

On behalf of the Alberta Disabilities Forum and all its members I'd like to thank you all very much for hearing us, and we welcome any questions you might have at this time.

The Chair: Thank you very much for a very informative presentation. We have a few minutes for questions.

Mr. Vandermeer: My mother-in-law had MS since she was 17 till she passed away when she was 85, and she was heavily medicated. Then my nephew became a pharmacist and looked into her medication and found that she was being overmedicated, and that was the reason she was always sleeping and tired. How would you react to a situation like that?

Mrs. Kristinson: Well, I think that many of the medications that have been used previously have contributed to fatigue, and fatigue is one of the most major symptoms that impact people with MS. You can have a very mild case of MS and be impacted by fatigue. When you look at some of the pain medications now – Tamina was talking about Lyrica – if you've got pain and you're on one of the old neuropathic pain medications, it's going to create more fatigue. The new lines are creating less fatigue, so people can use it and not have that same effect on their overall well-being. Like I said earlier, we were treating people symptomatically, but we've improved the drugs, and they are far more effective. We just can't access a lot of them. We're still using some medications that came out 25 years ago to treat the symptoms of MS today.

Mr. Vandermeer: Thank you.

Ms Notley: I was interested in your comments about the sort of cross-jurisdictional comparison with respect to drug funding in different provinces. You mentioned that Alberta is perceived as having some of the strictest approval criteria. Is that, in your view, the primary explanation for the lower level of funding in Alberta, or is there another mechanism in play that you would be aware of that we need to know about?

Mrs. Avdagovska: According to research that we did – we tried to compare everybody. Not to put down any province or anything like that, but what it showed is that there are certain drugs that don't get approved on the list here really fast, as in some other provinces they do. For example, the biggest comparison sometimes comes when the FDA will approve a drug. It will take years. That's why Michelle pointed out that 25-year-old medication is being used today rather than going with the new technology.

That's why one of our recommendations is to kind of get the plans going and get the drugs approved faster because what people need is what people need. I guess we're not supposed to say that the government will say that people will need it. That's why we don't need the caps on the benefits that come and what drugs get approved. Our statistics show that in some other provinces the drugs get approved faster as the needs of the people arise, and people bring to their physicians the needs that they have for their own personal well-being.

Ms Notley: Can I just ask one supplementary? When you say faster, can you give me an example? Is it sort of six months versus two months or three years versus 10 years? What are the gaps?

Mrs. Kristinson: I can answer from the perspective of MS with the medication Tysabri, that I had been talking about earlier. It's just recently been approved by Quebec. No other province has approved it yet.

One of the challenges that we're experiencing is the common drug review at the federal level. If a drug isn't approved through the common drug review, then provinces are very reluctant to look at the drug to go on the formulary when, in fact, a lot of the data that came from the company shows really good results. We're waiting for those common drug reviews to be approved, and there are a lot of flaws in the common drug review, so it really holds it back. It looks, you know, across the country like most provinces are waiting for the common drug review to make those decisions. So we're held in limbo at the federal level as well.

The Chair: Thank you.

Mr. Olson, please.

Mr. Olson: Thanks. Thanks for the information. As I read through your materials, there's one thing that I was kind of scratching my head on, and I'm hoping you can clarify for me. It relates to some studies that were done about the cost of prescription drugs. I think there's kind of a general sense out there that these are runaway costs that are going out of control, and governments can't afford to pay for them, and so on. I can't even read the page number, but there's a reference to the Canadian Patented Medicine Prices Review Board and their explanation for the increase in drug costs. They attribute these rising costs to a significant increase in the amount of prescriptions. They're saying, really, that the cost of the drugs hasn't far outstripped other costs that are also rising. It looks like they're suggesting that the real reason is that there are so many prescriptions.

I'm just wondering: would you agree with that, or would you challenge that notion? I think that's, you know, one of the things that we probably need to get a handle on. If we're going to try to solve a problem by accepting some of your recommendations, does that promote the prescription of more and more drugs where, at least to me, the inference is that they're maybe not necessary?

Mrs. Selig: I think what we're seeing when it comes to people with disabilities is that if they need a particular medication, I don't see them being overly prescribed. What I see is maybe a misuse in how that prescription is used. Sometimes there may be a person who, say, has a urinary infection due to whatever – they're in a chair, whatever happened – and, you know, in a week it seems to be all cleared up. So instead of finishing that prescription for what it is, the two weeks, and making sure that it's totally clear, it isn't because: oh, we can use that if this happens again. Then what happens is that the infection isn't totally cleared, so we do see a reoccurrence. A lot of it is the education on how to use the prescriptions. As far as what I've seen and what we've noticed, I don't think it's an overprescribed amount.

Mrs. Avdagovska: I just wanted to add to that. That's why we have recommendation 2. We believe that education is needed. People need to understand the medication they're taking with their physicians to get appropriate information about usage.

That ties into Mr. Vandermeer's question: his mother-in-law was overmedicated. Well, is there education about the medication? We want it. The Alberta Disabilities Forum is recommending it. We believe it's missing. That's why sometimes the studies show overuse, inappropriate use, and overdosage, and this is what adds to the cost at the end. If there is some kind of education set in place that individuals would be able to access with their physicians at the same time in order to understand that they have to use the two weeks of medication, that it has to be used at that point in time in order to prevent a future outbreak - that's why the ADF recommends that part. The cost barrier will be downsized if people use as much as they're told to use and not wait for the future because of money or because of the fear that there will not be any more or anything like that. I think there should be some kind of relationship with the physicians that should exist there, some kind of assurance that there will be medication if this occurs any time in the future.

Mrs. Selig: Just a further point that this education that we're talking about, I think a part of it needs to go to the physicians and to the nursing, to those individuals as well. That would be beneficial.

9:30

The Chair: Thank you.

I think we have time for one more question. Dr. Sherman.

Dr. Sherman: Thank you, Mr. Chair. Thank you, all, for appearing today. I'll just put my doctor hat on. Just speaking to medications and drugs in general, one of the challenges, especially in your area where drugs are so specialized, in general for pharmaceuticals, part of the problem, is the evidence that 30 per cent of the drugs that come out fresh have come into the market too quickly, and they're overdrawn.

To give you the example of anti-inflammatories – I won't mention any names – where the reasonable cost alternative was 15 cents a dose. Then, certainly, the newest drugs cost 10 to 20 times more than the older drugs that have worked. As policy-makers just putting the newest, latest, greatest drug on the market right away when the drug costs for every other illness are going through the roof, what happens is that the pharmaceutical companies – every physician's behaviour is changed with respect to, say, antibiotics. The latest, greatest antibiotic we have all this resistance to because there was inappropriate use of medications. Well, for policy what you need is the lowest cost, most effective drug with the least side effect profile most appropriate for the patient. One of the challenges for your specialized area is in the broader health system. Just because the costs are going up so much elsewhere, there has to be that due diligence to make sure that it's the most appropriate drug.

Just a comment on Tysabri. That is one of the most effective drugs long term for MS. What is the cost of that drug? I was just googling here on Wikipedia, just looking up the specifics of the latest drugs.

Mrs. Kristinson: The baseline cost is coming in at just under \$40,000 per year. Currently the other disease-modifying therapies range from \$14,000 to \$24,000 per year, so these are very expensive drugs. But when you look at studies that show the cost of disability, if you can delay the disability, the \$40,000 is such a small cost compared to someone's progression in requiring all the disability supports for the rest of their life.

Dr. Sherman: Now, I'm not specialized in MS. I'm specialized in emergency medicine. Is that a drug that's recommended for every patient or for certain patients you would pick, and is it a lifelong treatment?

Mrs. Kristinson: The treatment would come when the other disease-modifying therapies are no longer effective and you're acutely progressive. So if you're progressing at a rapid rate, it becomes the next line of defence. If you progress to the point where the drug is no longer effective, then there are no other drug therapies beyond that. That's sort of our next line of defence in terms of MS.

Dr. Sherman: Thank you.

Mrs. Selig: Just to agree, at one point that's what we are seeing, too, is that there is a large portion here that could be on, say, Robaxin because it's actually working better than something that is prescribed. That's why that recommendation came up for coverage for over-the-counter pharmaceuticals.

Dr. Sherman: Thank you.

The Chair: Thank you very much. I'd like to express the thanks of the committee for your appearing today and for, as I said, a very informative presentation. I'm sure it will be of great benefit in our future deliberations. We're sorry that time was so short. I'm sure this could have gone on for quite some time. Thank you very much for being here this morning.

We'll just pause for a few seconds while the next group comes up to the table.

We'll call the meeting back to order. I'd like to welcome in this segment representatives from the Glenrose Rehabilitation Hospital Foundation. Before I introduce our guests at the table, I'd just like to recognize a former colleague, a former member of the Assembly, Mrs. Mary O'Neill. Welcome. Nice to have you with us.

Mrs. O'Neill: Thank you.

The Chair: I believe we have seated at the table Dr. Ted Purcell, chair of the foundation, and Mr. Don Cranston, who is a member of the University of Alberta Hospital Foundation. Am I correct, gentlemen?

Mr. Cranston: Yes.

The Chair: Welcome, gentlemen. Thank you for being here. We have approximately 30 minutes, and we like to divide that between about a 15-minute presentation, up to 15 minutes, then leaving us an opportunity to ask you some questions and to engage in some dialogue. Please proceed.

Glenrose Rehabilitation Hospital Foundation

Dr. Purcell: Okay. Well, thank you, and good morning. On behalf of the Council of Foundations I would like to thank you for inviting us to give this presentation this morning. As Mr. Horne has mentioned, my name is Dr. Ted Purcell. I'm chair of the Glenrose Rehabilitation Hospital Foundation and also chair of the Council of Foundations. Joining me this morning is Mr. Don Cranston, who is volunteer chair of the University Hospital Foundation and a partner in the law firm of Bennett Jones.

Just by way of background the Council of Foundations was formed in 1998, and we are a voluntary association of health care foundations in the Capital health region. Our purpose is to foster a positive environment of health care philanthropy and to work in a co-operative fashion on matters and issues related to health care fundraising in the capital region. Being a charitable health care foundation, we form an important and integral part of the health care system in the province of Alberta. We facilitate community participation and partnership in many fundraising initiatives. I think, you know, that depending on where you come from in this province, you simply need to look in the newspaper or look throughout the community to see the important work that foundations do in communities throughout the province.

The Council of Foundations here in the capital region is comprised of 13 members, and I will leave a list of those member organizations with the clerk after our presentation. Joining us today are some executive members from the team and also volunteer trustees from those foundations, and we're grateful that they're here in attendance with us as well.

The purpose of Don and myself being here today is on behalf of the Council of Foundations to ask the government of Alberta to amend the Health Information Act to reinstate access to patient names and contact information for the purposes of grateful patient fundraising. I wish to highlight again the comment that this is to reinstate it. It's something that we have had in the past, and I'll get to that in just a moment.

Grateful patients are the base for any successful health care foundation fund development program. It is grateful patients that donate gifts of gratitude for the health care that has been provided to them. I draw you the analogy of postsecondary institutions who rely on their alumni after they have graduated to support the initiatives of the postsecondary institutions. I guess, in a way, what I'd say to you is that the grateful patients are our alumni. They are the people that we rely on through their time, through their talents, and through their financial resources to help enhance patient care and to fund research in the community.

I'd like to provide you with a little background on access to patient names in Alberta to help you better understand why we're here today making this presentation. Access to patient names had been a traditional aspect of fundraising for health care foundations in Alberta until about 10 years ago. Back in June of 1997 the minister of health at the time directed the regional health authorities to cease providing patient names and addresses to health care foundations in their respective regions. This directive was later included in the provisions of the Health Information Act.

9:40

Since 1997 the number of grateful patient donations in Alberta has significantly declined, and this has impacted the financial support that foundations receive today. I think it's not only the financial support that we receive up to today but also moving forward looking into the future. What it does is it also impairs the ability of foundations to develop long-term and in some cases lifelong relationships with grateful donors. These are the grateful donors who not only provide financial support; these are also grateful donors who will sit on the boards of the foundations and various committees to help the foundations forward their work in the community.

I'm going to pass things over to Don now to discuss with you some of those aspects and some examples of how lifelong and longterm relationships have benefited the foundations in the capital region. He's also going to review some of the changes that we are going to recommend to the Health Information Act.

Don, I'll pass things over to you.

Mr. Cranston: Thanks, Ted. Good morning, and thank you very much for allowing us to come and make this presentation to you. I should start off by being grateful to Ted for the promotion he gave

me, but it's not the case; I'm not the chair of the University Hospital Foundation. I'm one of the board members of the foundation. Our chair might take a dim view if I'd let that pass without correcting the record.

From a policy perspective there are, I think, two principles at play for you. It is our submission that those two principles can be brought together effectively without compromising either and, in fact, promoting both, and that is why Ted and I are here today to speak to you. The number one reason that people give, in our experience, is that they are asked or that they are grateful for something that they or their family members received. By way of example one donor to an Edmonton area hospital foundation made a gift as a result of health care given in 1994. It was a small gift, and it was before the time when the legislation brought in in 1997 precluded access to patient names. Since then that individual has donated very substantial sums of money and has provided in his estate planning some very sizable sums of money for the benefit of all of us accessing health care.

Another donor made a gift of \$50 in 1993 in gratitude for care received, again at a time when we were able to access patient names. That individual went on for many years to make similar-sized gifts, modest but important and every bit as important as the bigger gifts. Then when that individual passed away, a very sizable gift was left for that hospital foundation, again, for the good work of that hospital.

Whether it is the accumulated gifts of many small donors or transformational donations like the ones I've just described, all of these help to advance health care in Alberta. Freely-given dollars donated to our various hospital foundations generate a very significant percentage of discretionary revenue for the foundations that allow health regions to seize opportunities to recruit the best and to provide services that might not otherwise be available. As you can appreciate, the foundations are the primary vehicle for community members to make direct contributions to the health institution of their choice.

Since 1997, when the current restrictions came into place, as a consequence of those restrictions which were placed in the Alberta Health Information Act, foundations have not been able to access patient names and addresses, contact information, if you like, and that has had a very profound impact on the ability of foundations to raise money for these important projects.

We are here because we believe it is possible to achieve a balance between the need to protect patients' health care information, a principle that we support strongly, and to allow our hospital fundraising organizations to have limited access to patient contact information in order to offer them the opportunity to make charitable gifts in gratitude for care received by them or their families or friends.

Now, we do not stand alone in this. The majority of our population in Canada has this open to them. In Quebec it has been available for a significant period of time. I think some materials that you were given, Mr. Chairman, have a brief summary, and I'll leave with the clerk at the end of our presentation a very short summary sheet for the benefit of your committee members. In Ontario in 2004, in recognition of this disconnect, amendments were made to their health information legislation which afforded this access on a controlled and sensitive basis to maintain the protection of confidentiality, and that has been in place in Ontario now for some time. In Manitoba recently there have been amendments to their legislation in recognition of this problem, and what we really are here to do is to not be left behind. We hope that your committee and your government will see fit to make this available to foundations in a balanced way that protects health information yet in a proper, easy, controlled, and empathetic way allows access to the foundations.

The major elements of the legislation – and I know our time is restricted, so I don't intend to take any real amount of time on this – do achieve a balance. They do in a very understandable and careful way make it plain that patients do not need to be part of this. They can opt out at any time. There is obviously filtering that occurs. There are some circumstances where it would not be appropriate for health facilities or health care providers to be contacting patients. That, of course, it almost goes without saying, would not be something that the health care facilities would pursue. So this is not an open chequebook. This is a carefully designed access, recognizing the health information protection importance.

We will leave you with a brief summary of the three pieces of legislation that are currently out there: Manitoba, Quebec, and Ontario. Our commitment to you is to build within the system, should you and your government see fit to make these changes, appropriate mechanisms to work with you to the extent that we can and you wish us to be involved to help facilitate this proper balance and to make it work properly. We would work closely with Alberta Health Services to ensure that sufficient filters are in place to remove names of individuals from grateful patient programs that would be inappropriate to contact. I expect that all of us around the table would recognize readily some examples that come to mind. It simply wouldn't be appropriate, and there has never been an intent that that would be part of this program.

We would ensure that all correspondence through our grateful patient programs would include easy to understand information on how people can opt out. Obviously, people would not be contacted when they come to the facility or to the program for services. That's the kind of thing that simply would be inappropriate, to be talking to them about giving at a time when they are in need. That's the last thing in the world they need to hear about. That is not part of what we're proposing to you.

We believe that the recommendations we're leaving with you will ensure good public policy balancing and keep at the forefront the needs of patients for security of their health information while allowing very important foundations raising monies for our communities to do their work and to not have this decline ongoing where we as foundations are unable to access the names and contact information of the very people whom we are serving.

So it is, in summary, our recommendation to you and our request that you give serious consideration to recommending and taking forward an amendment to the Alberta Health Information Act to permit that balance to be reinstated and to allow the foundations to do their important work in a more meaningful way.

On behalf of Ted and myself I really do appreciate the opportunity to come before you. As I said, I'll leave with you some information. We also have a letter from the Association for Healthcare Philanthropy. It's a Canadian nonprofit organization that supports philanthropy in health care that is very supportive of this. We'll leave that with your clerk as well, Mr. Chairman.

The Chair: Thank you very much, gentlemen.

Just before we go to questions, two things. First of all, I'd like to recognize the fact that we have two former Members of the Legislative Assembly in the gallery. My apologies to Debby Carlson, who is also with us this morning. Nice to see you here, and I'm sorry I missed you earlier.

Then, gentlemen, just for purposes of clarity, for the record I just wanted to make sure that it was clear that this committee is a committee of the Legislative Assembly. It's an all-party committee; it's not a committee of the government. We don't have the ability to initiate recommendations other than under specific circumstances. Just as an example, if the Health Information Act was currently under review – say there was a bill in the Assembly proposing some amendments – the Assembly could make the decision to refer that bill to the committee for review. We don't have that situation at the moment, but that would be the mechanism by which the committee would make recommendations back to the Assembly, not to the government, in response subsequent to our review of the bill.

9:50

I just wanted to make sure that that was clear. I don't think that in any way means that the information you're providing us isn't of tremendous use and very informative, but if there are specific proposals that you have for the government of Alberta, those have to be directed to the government, to the appropriate minister, and I'm assuming that you're engaged in discussions in that line as well. I just wanted to make sure that that was understood.

I'll open it up now to questions or comments from committee members.

Mr. Olson: Thank you very much for the information. I'm interested in the context in which the decision was made back in 1997 to pass the legislation which caused you the problem. I guess my question would be: was there some argument at the time that the release of this kind of information was causing a problem, and that's the reason we ended up with these restrictions, or was it kind of like an unintended consequence? Do you have any information on what the arguments were at the time?

Dr. Purcell: Well, my understanding is the latter rather than the former, that it was more an unintended consequence, and I think we were swept up in part of the federal privacy laws as well. In a way, I guess, I would term it that I think we were collateral damage.

Mr. Cranston: That's my understanding as well. As you may recall, at that time privacy issues were coming to the forefront, and I think that's exactly as Ted described.

The Chair: Mr. Vandermeer.

Mr. Vandermeer: Yeah. I just want to thank you for all the good work that you've done. I think that this is one of the areas where government gets in the way of people doing good work. I want to commend you on that. I hope that we can move forward on this and that the information gets back to the right people and we make changes.

Thank you.

The Chair: Any other members? Questions? Mr. Dallas, followed by Ms Pastoor.

Mr. Dallas: Thank you, Mr. Chairman. Thank you for being here. While I can appreciate how much simpler this process would be if you could access the information you seek, I would like to just understand a little bit some of the strategies that you've deployed. You'd like to move to a system where potential donors would opt out of an engagement with the foundations. Could you give me some examples of the types of initiatives that you've had to try to engage donors to opt in? Is there any opportunity at the source, the point of the end of service delivery or at some other point, where you've been able to identify donors and give them an opportunity to opt in?

Mr. Cranston: I'll take a stab at it. It's a very good question. The short answer is that we do not have access to any names of patients.

For example, I'm associated with the University Hospital Foundation, so I'll speak to the University hospital. The University Hospital Foundation does not have access to any names of any persons receiving services at the hospital. None. So our fundraising efforts are not focused on any people, because we simply don't have the names, who receive services at the hospital. They have to be more broadly based. They have to be targeted to people that are seen to be philanthropists and then more broadly based programs. We've all seen the lotteries and the dinners and the campaigns and so on that are set in motion in the public. We can do those sorts of things, but we have absolutely no access to any names of persons who are serviced at the hospital. That was not the case before 1997.

The Chair: Thank you.

Ms Pastoor, followed by Dr. Sherman.

Ms Pastoor: Thank you. I would just like to comment that when I'm looking through the list that you've given us on behaviours of the different provinces, it looks like 6 out of 10 actually say: no access without expressed consent. How do you feel about the ability that people can either opt in or out if they don't want their names given to anyone?

Mr. Cranston: I think that's entirely appropriate. That's what we're suggesting. I think there needs to be that ability for people to say: I don't want to be part of this. When you look at it, you'll find that it's constructed in such a way that people have that right, and that right is respected.

Ms Pastoor: I'm sorry. I really don't understand how the process worked prior, probably, to '97. I go in, I have something done, and I come out. When would I be approached to say: "No. I don't know how you got my name."

Mr. Cranston: As I understand it, there would be several different ways, and this would have to be worked out and created so that it is entirely appropriate for each health care provider. An example might be that there would be appropriate notices on boards and so on. As I said earlier, there would not be, you know, contact with people directly about these issues while they are receiving services or in the immediate term after they've received services. At some reasonable point in time, to be sorted out and determined by the policy, if appropriate and if the filters allow for that person to be contacted - it may well be a person or a family that ought not to be contacted, and the filters would catch those people. But if it is a person that is appropriate to be contacted, they would receive in the mail, presumably, some information about the foundation and some very plain and easy-to-understand opportunities to just simply phone or e-mail or call back and say, "Please don't send me anything more," and they would be taken off the list.

Ms Pastoor: Thank you.

Mr. Cranston: You're welcome.

The Chair: Thank you. Dr. Sherman, please.

Dr. Sherman: Thank you, Mr. Chair. Thank you for appearing before us and educating us a bit and for all the wonderful work that foundations do, something that hospitals and government can't do, which is to provide the soul to a facility when people are at a weak moment in their lives.

In balancing patient privacy, I can, on the one hand, sort of understand that if you're in a cancer hospital, your name goes on a cancer list. In acquiring the patient information, for instance, if patients are in a prostate hospital, would there be separate lists that would be developed, or would it be a general list for a hospital or for a system?

Dr. Purcell: Well, those details, again, would have to be worked out based on the policy. It would be my view that it would be from the hospital.

Dr. Sherman: Okay. This is a follow-up. When patients check into a hospital, when patients sign a consent for treatment or perhaps when they're discharged from hospital, they could give consent to be contacted and at the same time get an opportunity for them to contact you. Have those avenues been explored, or would we have to go through legislation to make that happen?

Mr. Cranston: I'll take a stab at that. These things have not been, you know, set in stone. I speak for myself when I say that I would be very slow to think that having some sort of consent for fundraising activities would be appropriate when a person comes to receive services. It seems to me that that is not the time to be doing that for people. Families and individuals have other things on their mind, and we need to be sensitive to that. So it would be something that would follow from the conclusion of their care, whatever that might be.

With respect to your example of the Cross Cancer Institute, for example, or a prostate cancer program, that is part of the very important work of filters that would have to occur at the front end in setting up the system. A family experiencing a devastating illness with a child may well be the kind of thing that you would not want to allow this sort of thing to go through, at least in the near term. Cancer palliative care may be another. These kinds of filters so that we don't willy-nilly have people receiving letters are an important feature of the program when it would be set in motion, and each institution would have to look at what is appropriate for its patients and deal with it.

They would not be required under our proposal to give health care information. They would be enabled to give identifying information, name and contact information. Obviously, no health care information would ever be provided.

10:00

Dr. Sherman: Thank you.

The Chair: Thank you very much.

I think that about exhausts our time this morning, but I'd like to thank you both, gentlemen, very much for the presentation and for engaging in the dialogue with us and also to your colleagues from the foundation who have joined you in the gallery. The information has been very helpful, and we appreciate your time and your interest in the committee. Thank you very much.

Dr. Purcell: Thank you.

Mr. Cranston: Thank you.

The Chair: Just for the committee, we'll take approximately a fiveminute pause here while we change groups and give you an opportunity to grab some coffee if you wish.

[The committee adjourned from 10:01 a.m. to 10:07 a.m.]

The Chair: Thank you for waiting, ladies and gentlemen. I'd like to call the committee back to order. Apologies for the delay. We convened at 8:30 this morning, so as chair I thought it was the least I could do to give people five minutes.

I'd like to welcome representatives from Campaign for a Smoke-Free Alberta – I'm sorry; from the Alberta Provincial Respiratory Strategy. My apologies. A little ahead. I'll put on my glasses here.

Just in the interests of time – we have approximately 30 minutes here – we'd like to divide that between approximately a 15-minute presentation, for which I'll move away from the screen, and up to 15 minutes for questions and dialogue with the committee. I'll just dispense with the introductions of the committee members. You see our name placards. Thank you very much for coming. I'd just perhaps ask you to begin by introducing the representatives at the table.

Dr. Befus: Yes. My name is Dean Befus. I'm the director of the Alberta Asthma Centre and a lung health researcher at the University of Alberta. I'm very pleased that I have colleagues Dr. Brent Winston from the University of Calgary, a practising lung health physician and respiratory care physician; Dr. Bob Cowie, from the University of Calgary as well, a professor of medicine and a lung health physician; Gina Ibach from the Lung Association of Alberta and the Northwest Territories, who is the vice-president for health initiatives. I'm very pleased that Tony Hudson, the CEO of the Lung Association, is also with us on the side.

The Chair: Okay. Thank you. Well, with nothing further, I'll ask you to proceed.

Alberta Provincial Respiratory Strategy

Dr. Befus: Okay. Well, thank you tremendously for the opportunity to present what we think is a very exciting initiative and that has involved the activities of a large number of people over about two years. Indeed, about 150 stakeholders, including physicians and other health care professionals, researchers, and administrators, have been involved in the development of this strategy that capitalizes on what is tremendous expertise in the province of Alberta and what we see to be a very significant need in the province and an opportunity. We've involved in this process all the health regions in the province and capitalized on the expertise, and indeed in what is clearly unprecedented collaboration in the province, this group has come together to put forward this proposal, that we think is a very significant opportunity for all the people in the province and for the government.

I'm going to pass now to Dr. Cowie to make the formal presentation.

Dr. Cowie: Thanks, Dean. Thank you very much for agreeing to meet with us. We really appreciate it.

The slide that's up now shows you the major organizations that were involved in this initiative, but as Dean has pointed out, it goes far beyond these four organizations to pretty well every corner of respiratory health in the province. In the documents in front of you you see a predominance of physicians, but in our deliberations we really had input from people involved with the respiratory health of Albertans of every sort, including indeed a few representations from the patient population in Alberta.

Alberta Breathes was the title of our initiative that we've developed. It was really created to facilitate excellent care for Albertans with chronic respiratory disease. You'll see as we move along that we've identified three chronic diseases as being the most common and the ones that really require our urgent attention. The background is up there: our health service is designed to treat acute aspects of chronic respiratory diseases. I've said there: an expensive and futile strategy. I can't take credit for that comment although it is what I said. I'll take you back – maybe it's a little bit too old – to the Mazankowski report of 2002, and in that there is what I think many would have taken to be quite a startling statement. It says, "Too much of the focus in our health system is on treating people when they're sick." I think that that just says it all so beautifully. Everything we do in health services is delivering health care to people who are ill as opposed to providing health care. I think that to me that's such a striking comment.

If you look at the mandate of the minister of health, Minister Liepert, you'll see the same thing coming through, that we want to increase access to quality health care and improve efficiency and effectiveness of the health care service delivery. I think these are elements that we really haven't addressed sufficiently, certainly in the area of chronic respiratory disease. We wait until people fall off the wagon before we pick them up and fix them instead of trying to make sure that the load is well secured before that happens.

We want to address these diseases – chronic obstructive pulmonary disease, asthma, and obstructive sleep apnea – by offering early and appropriate diagnoses so that we can identify these disorders and address them before people get sick and really engage the people suffering from the disease. We've said: patient participation. We probably shouldn't even call them patients. They should be prepatients, hopefully not to become patients. Engaging them in the management team: this is something that has been done extensively but in little cells all over the world and also in Alberta. Then, clearly, also very important, we need to keep evaluating the process to make sure that what we're doing is achieving the outcomes that we need.

The next slide, the question of why Alberta needs this initiative. I think maybe some figures to throw at you first of all. If we take chronic obstructive pulmonary disease, it's been estimated that that affects between about 150,000 and 200,000 Albertans over the age of 40. If you take asthma, asthma is the most common chronic disease, not just respiratory but chronic disease, in Canada, and it's not surprising because it affects people of all ages. You know of infants with asthma; you know of 80-year-olds with asthma. It's been guesstimated that in Alberta – we don't have precise figures – we're looking at 5 to 8 per cent of the population having asthma, so in any given classroom you're going to see two, three, four children who have asthma.

Another statistic that I think is really meaningful in asthma and emphasizes the need for us to be addressing people with asthma before they get sick is the fact that every 16 minutes someone is treated in an emergency department in Alberta for asthma. Data shows that 90 per cent, maybe 95 per cent of acute attacks of asthma requiring treatment in emergency rooms are preventable. So with appropriate management, certainly appropriate self-management, people with asthma should never need to go near an emergency department and certainly should never need to be admitted to hospital.

10:15

The size of the problem in obstructive sleep apnea is also great, with an estimate of between 80,000 and 100,000 people in the province with this disease, 80 per cent of them, as we speak, not yet diagnosed. Therefore, it's a problem that hasn't been addressed. This is a disorder, it says here, with increased risk of heart attacks, high blood pressure, stroke, and motor vehicle and occupational accidents. It's certainly a disease worthy of our attention. In all, we're looking at between a very conservative estimate of 400,000 but more likely 600,000 people in this province suffering from one of these three diseases. It's certainly a sizable problem.

Our goal statement is pretty straightforward, that every Albertan with chronic respiratory disease be identified and treated using best practices to arrest progression of the disease, reduce the burden of the illness, and particularly reduce acute-care sector involvement. At the moment the amount of money being spent on caring for people with acute aspects of these diseases is huge. It's been estimated, for example, that maybe as much as \$1.25 billion is spent a year in Alberta on COPD. Those are direct and indirect costs. It's a total estimate of \$1.25 billion, and when you look at that in the context of the total health budget, that's a huge chunk of money. It's the only chronic disease - the only chronic disease - including cancer, stroke, and heart disease, where mortality is actually increasing, and it's projected to be the third cause of mortality in the next half decade world-wide and certainly in Canada. It's a big disease with a lot of opportunity for us to actually address it before it ever gets to the stage of needing acute-care facilities.

I should just mention that Alberta is very well blessed with people who are expert in respiratory health care delivery. We actually have a much higher proportion of people, for example respiratory educators, per capita in Alberta than any other province in the country. Many of the Albertans involved with respiratory health care delivery are recognized nationally and, indeed, internationally. We have the expertise. We just need to have the process to try and provide a system for helping people with these chronic diseases across the province, not just in pockets of Calgary or wherever but more widely available.

What will the strategy actually do? In essence, it will extend the service provided. For example, if you look at the chronic disease management program in Calgary, it's the envy of many cities throughout Canada. It's an excellent system. But if you happen to live just outside Calgary, you don't have access to those resources.

The whole idea of Alberta Breathes is to try and make these resources that have been evaluated and have been shown to work available to Albertans throughout the province. With the personnel we have, with the expertise we have in telehealth, and with the simple interventions that we are proposing, we certainly think that this is feasible and that it's achievable as a net savings in terms of health care expenditure for chronic respiratory disease. We expect that we will be decreasing emergency visits, improving patient or, should I say, prepatient care, certainly improving quality of life, and overall reducing global health care costs.

How are we going to do it? I've addressed some of that already. Let's take the example of COPD. This is a disease that can actually be diagnosed decades before the patient ends up disabled and in hospital. It can be recognized in a 40-year-old who, by the time they get to 60 or 70, will be ill from this disease, be disabled and not able to work and costing us money. If we can extend the resources for diagnosing this disease, a simple test called spirometry, we can identify people's disease long before they ever come anywhere near our hospital horizon. This is an intervention that is inexpensive, is unfortunately at the moment of limited availability, but with the right resources and working with government, we believe that we can take that particular resource right province-wide and be able to address the 15 per cent, maybe 19 per cent of Albertans over the age of 40 who have COPD.

Then, finally, to get to the money side, we've estimated that it would cost us - and I think if you have our Alberta Breathes document, there's some breakdown of the budget on the final page. We've estimated that \$20 million over two to three years will allow us to develop this program and make it sustainable and feasible. As

I say, we have the expertise. For the most part we have the resources. It's a question of making them more widely available. Exactly how that should be done: we defer in part to your expertise because I think that we don't have a clear image of exactly where government wants to go with health care in general, but I think that with the expertise that we have together with the expertise from government, this is certainly an achievable goal. We think that that would be the approximate initial cost of this venture. Then once that's established, our expectation is that we would start to see a return in terms of improved health and reduced costs.

Thank you for your attention.

The Chair: Thank you very much for an extremely informative presentation. We have some time for questions, and if my colleagues don't mind, I would like to ask a question. I was very heartened to see a quote from the Mazankowski report. In fact, if I recall correctly, the first words in the report are, "The first reform is to stay healthy." I'm wondering in terms of how a strategy like this would be integrated in a provincial health system.

I'll just sort of go back a bit. When I started out professionally as a health planner in the early '80s, health promotion – and this was in another province – consisted of, you know, holding a sign in front of someone and saying: smoking is bad for you. It was not an effective strategy. In the last several years, in primary care in particular, Alberta has developed some very innovative models across the province involving multidisciplinary teams, many of which I think are becoming increasingly focused on the management of chronic disease. I know you've given us some good idea of what the strategy entails and what the cost would be. I'm just wondering if you've identified any opportunities in the existing models that we have out there to operationalize the strategy.

Dr. Cowie: Well, that's a very good point of view. We look with great interest at the primary care networks, for example, that are developing, and we've already in parts of the province started to assist them in various ways for developing the sort of strategy that we have in mind. There are all sorts of opportunities. Wherever you go, there'll be some existing initiative that you can build on.

If we look at Red Deer, for example, we've got some really expert respiratory educators. So that's one really important component, that we, as you say, don't just put up a placard. We now are much more effective in our way of having patients, people, become part of the management team for chronic disease. If you come to Edmonton, Dean has developed the Asthma Centre, where the focus has been very much on educating children about their asthma, extraordinarily effective interventions. So you could build around all these existing components and expand them into other areas and develop them further.

10:25

Dr. Befus: Brent, would you like to

Dr. Winston: Yeah. Sure. It's not just primary care networks. I mean, in today's day and age, whether it's web-based educational phenomenon to access all of the hamlets throughout the province, that's one thing. The other thing is our health care educators. We're not looking to build an edifice that would help educate people. It's putting people where the patients are. Let me give you an example right now. My brother who is a pharmacist brings in a nurse once a week to deal with the diabetic patients: diabetic feet, et cetera. There's no reason that we couldn't train people to take on the same roles – we just have to have access and the resources to do that – as a respiratory health educator that would deal with COPD, asthma, and sleep apnea in the same vein that they deal with diabetes.

A lot of that thought is building upon some of the chronic disease management that we have, some of the resources that are available but also building a little bit more in terms of respiratory resource development from a human perspective.

Ms Ibach: Another example is the Palliser health region. The medical officer of health there instituted a simple policy that any patient that is over 45 years of age or has quit smoking in the past 12 months may have a standard spirometry, so that will facilitate early diagnosis in advance of symptoms, as Dr. Cowie mentioned earlier. It's just a simple policy that the respiratory therapy department is keen to support. We have a lot of motivation by health care providers throughout the province in various aspects. We just need some provincial co-ordination and leadership.

Dr. Winston: Your misidentification of us in the beginning was really not, because we very much participate in a smoke-free Alberta. That from a COPD perspective is a huge primary initiative that all of the people have identified as something that has to go forward as part of whatever management strategy that we have.

The Chair: Okay. Thank you. I know some other colleagues have questions.

Mr. Fawcett: I see that the slide in your presentation said that implementation of such a strategy would require a \$20 million investment from the government. You know, that's certainly challenging to us as policy-makers and as people that are responsible for delivering and organizing and budgeting public funds. I think that there are a number of initiatives out there that would be beneficial to undertake in the short term that might cause some short-term increases in cost to serve the long-term interests.

The challenge is that we already have a budget where we spend more per capita than any other province in this country, and we have a health care budget that is already well over a third of our total budget, so we're under a lot of pressure when it comes to the budget. I'm trying to get to a question here. What sort of policy mechanisms or very high-level achievements would you like to see this government go towards in implementing these types of programs, where we know that there are going to be some short-term costs for some longterm gains? I think that what we do need to do in our health care system to sort of stem this tide of exponential growth in our costs is look at long-term strategies, and that means that we might have to incur some short-term pain on the cost side.

Dr. Cowie: Yes. I think you've summarized that very well. What's interesting is that in the *Globe* today and, I guess, on the news last night there was an example of how putting in some of the resources that we have in mind can have a very quick return. I think they were citing a study from elsewhere in Canada that showed that 30 per cent of people who are consuming expensive resources – hospital resources, medication resources – for the treatment of asthma actually don't have the disease and that simply doing the spirometry on them for the cost of \$15 or something of that sort rapidly has taken them off the expense map. So I think there can be some short-term gains. Certainly, our major thrust is on long-term gains.

Dr. Winston: Also, the other short-term gain is to unload some of our acute-care emergency departments by undertaking some of these initiatives because that's where the pressure is right now, tremendously, not only on personnel but also costs. I'm unlucky enough to see the end result, the people that wind up in the ICU, and many

people can avoid getting into that expensive care, particularly if they're treated appropriately up front and early. I think that's where we would see some short-term gains in what we do for sure.

Dr. Cowie: Yes. I think, if I could just add to that, that in this context there's some data showing that very simple self-management education can keep people with COPD out of hospital. I think some of the data suggests that for a \$2 expenditure in education there's a \$7 saving. So fairly inexpensive but effective interventions can give you quite a quick return.

The Chair: Thank you.

Mr. Fawcett: Just a follow-up. I guess that from a policy perspective, what policies can this government put in place to allow strategies such as yours or innovations such as, let's say, insulin pump therapy for type 1 diabetes, that do require some upfront costs? What sort of policy mechanisms and accountability mechanisms are out there that are options for us as legislators?

Dr. Winston: Well, the first thing – and Dr. Cowie talked about it initially – was that if we had available spirometry, which clearly is something that could be easily made available, then at least the diagnostics and management up front would be something. That would be policy because it does require at least a little bit of expertise and right now is not available in a lot of places. So that's the simplest initial step.

The other thing that we've created was a steering committee to help push this forward, for which we thoroughly expect government to be involved, and built into this strategy is evaluation of what's being done on a regular basis. If you look at the budgeting, there's a fair amount of budgeting that's evaluating ongoing how we're successful and maybe not successful at changing strategy, et cetera. The other thing is that we don't even know the scope or magnitude of the problem, so acquiring some of that data is also very important. That's the feedback loop that we need to make things more efficient.

The Chair: Thank you. I'm just being a little conscious of the time here and trying to get as many questions in as we can. Mr. Olson, please.

Mr. Olson: I think he's telling me to be brief. No small challenge for me. But I'm just looking at the investment page that you have here. Out of the \$20 million over two to three years, I'm still kind of trying to understand exactly what the money would be spent for and what happens at the end of the two to three years because I would assume that there would be some ongoing obligation, a financial commitment. How much of this is for capital expenditure? How much of it is for staffing? What happens at the end of the two to three years? I might just say, too, thank you for the education. This has been fascinating for me, and I think it is very worthwhile information for us to have.

Ms Ibach: In the diagnosis and management section of the budget some of the items are things such as central project deliverables, working with system design, networks and pathways of care, so again really pulling together all these little pockets of excellence and being able to expand. We don't foresee a lot of capital expenditure, just an expansion: expansion of diagnostic testing, expansion of health care providers who are trained as educators and who deliver the education service. We also see targeted education programs to target demographic groups as well as high-needs groups, very specific, I mean, and also public awareness, public education.

10:35

Dr. Winston: Also, part of that is that it's not just a one-way. There's a dialogue, meaning that people need access to be able to get the diagnostics and the information that they need. Whatever networks that are built, it's a two-way street: feeding into the availability of getting what they need, bringing it closer to them for their self-management and education. A lot of that is building on the networks, the education side of things. It's not constructing new facilities.

Dr. Cowie: Sorry. I'm trying to be brief. For example, if we look at this set-up in Calgary, where there are community rehabilitation programs which are used for all chronic diseases but particularly, in our instance, chronic obstructive pulmonary disease, it would cost some money to establish programs like that. But all of these are being carried out in community centres, rec halls, and suchlike. It's just really a question of bringing in the expertise, and a lot of that expertise can actually be telehealthed in. I think that Fred MacDonald here in Edmonton has shown that you can actually have a rehabilitation program out there directed by someone back here using telehealth. There are lots of resources. I think the capital expenditure will be there, but it's not going to be a huge part of it.

The Chair: Thank you.

I'm sorry. I'm afraid we're going to have to leave it there. We still have another group to follow. I'd like to thank all of you very much for being here today, for your interest in the committee, and for what was just a wonderful, informative, well-thought-out presentation. Very helpful. Thank you, again.

Dr. Befus: Thank you very much.

Dr. Cowie: Thank you.

The Chair: Okay. I'd like to call the meeting back to order and introduce Campaign for a Smoke-Free Alberta. They have a number of representatives here this morning. I believe that you're aware of the process. We're looking for approximately a 15-minute presentation and then to leave some time for questions and dialogue with the committee. I'll recognize Mr. Hagen. If you'd care to introduce the other representatives with you at the table, that would be appreciated.

Mr. Hagen: Thank you, Mr. Chairman. Joining me this morning are Donna Hastings from the Heart and Stroke Foundation, Barb Olsen from the David Thompson health region and the Alberta Public Health Association, Dr. Fred Ashbury from the Alberta Cancer Board, Angeline Webb from the Canadian Cancer Society, and Tony Hudson from the Alberta Lung Association, and we've got a few others joining us here in the room for support if we need it.

The Chair: We're very pleased to have you. Please proceed.

Campaign for a Smoke-Free Alberta

Mr. Hagen: Thank you. The Campaign for a Smoke-Free Alberta is a coalition of 11 prominent health organizations who share a common goal in reducing tobacco use in Alberta. We welcome the opportunity to present to your committee, and we look forward to working with you to help improve the quality of life of Albertans.

Tobacco use exacts a very heavy toll on Albertans, and it is the single most significant cause of preventable illness, disability, and premature death. Each year 3,000 residents are sacrificed to

tobacco, and these deaths are completely preventable. This number corresponds to about 1 in every 5 deaths. Imagine if 1 in every 5 Albertans was dying from tainted water or from the West Nile virus and the response it would generate from our policy-makers and health officials. Unfortunately, we've become conditioned to the health impact of tobacco use because it is so ubiquitous.

The ripple effect from tobacco use is enormous, and it places a huge burden on individuals, families, communities, and workplaces. Unfortunately, the overall number of smokers in Alberta has increased in recent years, due in part to our population growth and, until recently, a provincial policy void. Tobacco use also has a huge impact on our economy and on our health care system. In 2002 \$471 million was spent on treating tobacco-related diseases. Today's number would be significantly larger due to increasing health care costs.

However, the largest financial impact of tobacco is on the overall economy. Tobacco drained the Alberta economy of \$1.3 billion in 2002 as a result of reduced productivity resulting from illness and premature death. Health and productivity go hand in hand, and tobacco use is impeding our economic output and our quality of life. Of course, it is impossible to quantify the human impact of tobacco use in our province.

Smoking rates among adults have declined since the Alberta tobacco reduction strategy was launched in 2002, as you can see in the chart. Unfortunately, the progress has slowed, and our smoking rates have now plateaued. The major decline in 2003 can be attributed largely to a \$2.25 per pack tax increase and the launch of the Alberta tobacco reduction strategy. Despite this early progress, we have since encountered significant challenges such as the absence of meaningful provincial legislation until 2008.

The smoking trends among teens aged 15 to 19 are particularly disturbing. Again, despite early progress, we have witnessed an increase in youth smoking rates in the past few years. We simply cannot accept elevated smoking rates among Alberta youth. The status quo is not an option.

This slide portrays per capita consumption in Alberta based upon actual shipment data supplied by Alberta Finance. Once again we can see a slowing of progress since 2003. Fortunately, consumption dropped slightly last year as a result of the April 2007 tax increase. Hopefully this event has signalled a turning point in tobacco consumption. We expect that last year's passage of the Tobacco Reduction Act will have an impact on smoking rates in 2008. However, it is clear that further action is needed to drive down smoking rates in the province, especially among youth.

Before addressing the required actions, we would like to review some of the major successes of the Alberta tobacco reduction strategy to date. As indicated previously, tobacco use has declined significantly among adults since the strategy was launched in 2002. In our opinion, the 2002 tobacco tax increase, the launch of the strategy, and the Barb Tarbox media campaign that followed contributed significantly to this early decline. Municipal smoking bans also began taking effect in the early 2000s and likely contributed to the decline. The Alberta tobacco reduction strategy has created a concentrated and better defined tobacco reduction effort, and it has resulted in enhanced programs and delivery.

Fortunately, we now have meaningful provincial tobacco legislation. We commend the Alberta government and the Legislative Assembly for approving world-class tobacco control legislation that has helped to set the stage for further reductions in tobacco use. In the absence of meaningful legislation Alberta was fighting tobacco with one hand tied behind its back.

However, a number of significant challenges remain. We cannot expect the new act to make up for a five-year policy void and for the emergent problem of tobacco affordability. The affordability of tobacco in Alberta is currently the single largest impediment to reducing tobacco use, and a major tax increase is needed immediately.

Tobacco as a product remains largely unregulated. Although the packaging, sale, and marketing of tobacco is regulated, the product itself has virtually escaped regulation. Controls are needed on tobacco flavourings, additives, and toxic emissions.

Many people are surprised to learn that tobacco advertising is still allowed in Canada. Although tobacco companies can no longer use lifestyle images, they are still able to portray their product in a positive light in newspapers, magazines, public displays, and posters.

Another major challenge is the need to adhere strictly to available evidence and best practices in the development and delivery of tobacco control interventions. This aim should be a mandatory requirement of the Alberta tobacco reduction strategy.

For your reference here's a recent tobacco ad that appeared in newspapers and magazines across Canada.

Speaking of challenges, this graph displays the projected smoking rate in Alberta in 2012 if current trends persist. At the bottom right you will see the new target for the Alberta tobacco reduction strategy, 12 per cent. The difference between the projected smoking rate and the new target is striking. The new Alberta targets are extremely ambitious. Unless we redouble our efforts, we are very unlikely to reach these outcomes in just four short years. We may even have difficulty meeting our previous target of 17 and a half per cent.

10:45

Governments must hold tobacco companies to account. The tobacco industry has an unparalleled track record of deceit, denial, and public harm. The courts provide an appropriate mechanism for governments to seek retribution for this objectionable behaviour. We should also be telling the truth about the tobacco industry in our media campaigns. The public has a right to know how tobacco companies are targeting kids.

This slide portrays the tobacco affordability problem in Alberta. Among Albertans age 15 to 24 it only takes 44 minutes of labour to purchase a pack of 25 premium cigarettes compared with 70 minutes in Nova Scotia. Further, it only takes about 30 minutes of labour for young Albertans to purchase discount brands. Three factors are contributing to increased affordability: tobacco discounting by manufacturers, modest provincial tax rates, and higher wages compared with other provinces. A major tax increase is needed to reduce tobacco affordability among youth in this province.

Alberta also taxes cigarettes and loose tobacco at different rates on the basis of cigarette units. Tobacco companies have exploited this oversight by expanding loose tobacco so it takes less tobacco to make a cigarette. This marketing ploy amounts to a blatant tax dodge, and this loophole must be closed. I've got a sample here this morning. You might remember that tobacco cans used to be about half this size, and they used to make a hundred cigarettes. Well, they have expanded the tobacco. It's the same weight, but they use a freeze-drying process to puff it up. You can now make 200 cigarettes at essentially half the tax of previous forms of loose tobacco. This is a tax loophole that has to be closed. The tobacco companies are exploiting it.

Six provinces have now passed legislation to recover health care costs from tobacco companies resulting from deceptive marketing practices like the promotion of so-called light cigarettes. The B.C. legislation was challenged unsuccessfully all the way to the Supreme Court and now provides a template for other provinces to follow. B.C. and New Brunswick have already launched lawsuits. The New Brunswick lawsuit is being waged by a consortium of blue-chip law firms at no cost to government.

The Alberta government must hold the tobacco industry to account if for no other reason than to offset the tremendous health care costs resulting from tobacco industry products. If not, the Alberta government may leave Alberta taxpayers on the hook for billions in forgone damages. Under the Hospitals Act the Alberta government currently recovers health care costs from auto insurance companies for medical treatment resulting from traffic collisions. Tobacco companies should not receive any preferential treatment.

The sale of flavoured tobacco products has skyrocketed in recent years, and we've got some samples to pass around this morning. With flavours like cherry, chocolate, grape, raspberry, tangerine, and cinnamon it's not hard to establish who these products are aimed at. Tobacco companies are using flavours to attract young smokers and in some cases to make it easier for young people to start smoking. Flavour additives mask the harshness of tobacco products and tobacco smoke, increasing palatability and acceptability. Menthol also serves as a bronchodilator and allows more smoke to get deeper into the lungs. Governments must crack down on all tobacco flavourings to prevent tobacco companies from getting more kids hooked on their deadly products. Lung cancer and emphysema should not be sugar-coated or candy flavoured.

This slide we're looking at compares some common children's products, including markers, lip gloss, and gum, with the new flavoured tobacco products that are currently on the market. Can you tell the difference?

Here are a number of flavoured smokeless tobacco products. They're being distributed as well.

The increase in the sale of small flavoured cigars, or cigarillos, that we're distributing, is particularly of concern. As you can see, Canadian sales have increased by more than a thousand times – a thousand times – since 2001, and 60 per cent of cigarillo users are teenagers. Cigarillos often sell for just a loonie or two.

I'll now conclude with our specific recommendations. To reduce tobacco affordability, we recommend a short-term tax increase of at least \$2 per pack on 25 cigarettes and the equalization of tax rates on loose tobacco. We also recommend applying the revenue derived from a tax increase toward enhanced tobacco reduction programs and the creation of a dedicated health promotion foundation. We also urge the Alberta government to approve enabling legislation to permit medicare cost recovery lawsuits against the tobacco industry and subsequently to sue tobacco companies for the medical treatment resulting from their deceptive marketing practices. We also recommend an amendment to the Tobacco Reduction Act that would prohibit all flavourings, including menthol.

Regarding the Alberta tobacco reduction strategy, we recommend that the government set achievable targets with a coherent and welldefined plan to get there. We also recommend strict adherence to best-practice programs and policies.

In closing, no single program or policy measure can be expected to solve the tobacco problem. All of the above measures are needed in tandem to achieve meaningful results and to improve health outcomes.

Thank you.

The Chair: Thank you very much, Mr. Hagen.

We've got time for a number of questions. I've got Mr. Denis.

Mr. Denis: Thank you, Mr. Chair, and thank you to all the members for attending before our committee. I'll be very brief as we do have to get to caucus shortly.

The flavoured tobaccos that you have sent around here: is there a way of tracking as to who's mainly using them, if they are indeed an entry-level product? To be devil's advocate, I have seen many people smoking different types of flavours, be it menthol or rum-tipped cigars, that are very expensive and obviously not targeted to children.

Mr. Hagen: According to data supplied by Health Canada, through two surveys, the Canadian tobacco use monitoring survey as well as a youth smoking survey, about 60 per cent of users are teenagers under the age of 20.

Mr. Denis: Okay.

The Chair: Thank you. Dr. Sherman, followed by Ms Notley.

Dr. Sherman: Thank you, Mr. Chair, and thank you so much for presenting today. If you look back at the '70s, the Marlboro Man got all these young people smoking, and guess what happened to him? He died of lung cancer, and all of his friends who took up smoking are the ones sucking up health care costs. I think your figure of \$471 million is low. Seventy-five per cent of health care costs are from six major diseases – four of them are asthma, COPD, coronary artery disease, and cancer – and cigarette smoking has been implicated in many of them. I personally think that figure is a lot higher than you have.

Mr. Hagen: Well, the data we have is from 2002, and generally speaking, these are conservative estimates.

Dr. Sherman: I'd have a question for you. Smoking rates have dropped from 40 per cent into the 20 per cent range from the '70s till now. Of this last, these are the tough ones to get because as a physician you see that many of these people actually have addictions. Do you have any evidence as to how much taxes at this point are going to reduce it and how much more intensive treatment on addictions is actually going to reduce the smoking rates? Do you have any evidence from across the country or across the world to that effect?

Dr. Ashbury: Thank you very much. In California they've discovered, like you were speaking to, the issue of comorbid conditions of people who smoke, and this is the toughest community now of smokers that we've ever had to face. Part of our rationale in this strategy is to keep kids from smoking so that they don't become part of that tough group, of course. The other side of the question is: what can we do to spend money on areas for these comorbid conditions? They've found that when they've actually increased taxes and applied the monies towards programs that assist around the comorbid condition, rather than assuming that an increased tax is going to make a person who's heavily addicted to tobacco stop smoking, instead they focused on treatment-related approaches to it and had success with it.

In fact, in a very recent meeting, last week in Toronto, on tobacco the California people urged us, basically, to make the approach on the assumption that people recognize that this is a hard-to-treat group, and therefore you have to deal with their comorbid conditions and use the tax dollars around the treatment of the comorbid condition to help with tobacco reduction.

10:55

Dr. Sherman: With the young people that are smoking, what percentage of them are doing it just because it's cool and it's fun, and what percentage of them are actually addicted already?

Dr. Ashbury: What's staggering is that this has moved down to the elementary school levels, where most school surveys have shown that roughly 40 per cent of kids are reporting that they are at least occasional smokers. That's staggering, in my mind.

Mr. Hagen: Addiction can set in after just a few cigarettes, so it's highly addictive.

Just further to Fred's point about dealing with the tougher crowd as we move forward, keep in mind that we have not exhausted all of our policy and program options here, far from it. There are a lot of evidence-based strategies still on the shelf waiting to be applied, and until we've exhausted all of them, I would contend that we don't know what we're going to be faced with after that and how difficult that crowd will be to reach or the size of that crowd, hopefully less than 10 per cent.

Dr. Sherman: Thank you.

Dr. Ashbury: Yeah. Our problem has been, basically, that tobacco companies have relied on the risk-averse nature of governments to make policy, and they are highly adaptive. As we're seeing the changes now in smoking rates increasing among older teenagers and young adults, it's because of the effective use of the strategies that they have been doing to get around our loopholes. So if we have made the concerted effort to try to put one more bullet in our arsenal, I guess, or one more weapon in our arsenal to deal with these companies, that's one more thing that we've done to protect youth.

The Chair: Thank you.

We have time for two more questions. Ms Notley, followed by Mr. Olson.

Ms Notley: Thanks. I'm wondering if you can tell me if you know about the success or the experience with respect to actual sort of collection or awards of any of the medicare cost-recovery legislation in any of the other jurisdictions. I know they've been upheld, but have any of them actually played out with any success?

Mr. Hagen: Well, in the U.S. about 10 years ago every single state managed to settle with the tobacco industry for fear of lawsuits from the industry. Those settlements included a \$250 billion award paid over 25 years that had the effect of a \$1 per pack price increase on cigarettes across the U.S., which had a tremendous impact on consumption. Through those settlements various governments were also able to negotiate controls on tobacco marketing and promotions, and we could expect to do the same here in Canada.

Ms Notley: Have we had any outcomes yet of any of the ones in Canada?

Mr. Hagen: No. Our suits are still under way, the B.C. lawsuit and New Brunswick lawsuit. To be honest, I think they're waiting for other players, including big players like Alberta, to join in. Keep in mind that that New Brunswick lawsuit is being launched absolutely free of charge on a contingency basis: no fees, no expenses. And it's a blue-chip consortium of Canadian and American law firms that are just pounding on the doors of all the provincial governments right now willing to help you prevent taxpayers from having to pay billions in foregone damages.

Ms Notley: Thanks.

The Chair: Thank you.

Mr. Olson: Thanks for all this great information. In reading through your materials, I was interested in your proposal that there be an arm's-length, independent health promotion foundation created. Are there precedents for that elsewhere in the country?

Mr. Hagen: There are globally. In the state of Victoria, Australia, they have what's called the Victorian Health Promotion Foundation. That was established through an increase in tobacco and alcohol taxes about 20 years ago. They have achieved some amazing results in improving the health of their population. There's one in Thailand; there's one in Austria. So these things do exist.

This is one thing where Alberta could truly take some global leadership by setting up such a foundation, and you could fund it absolutely free of charge with another significant tax increase on cigarettes. You don't necessarily have to earmark those taxes – the finance people don't like that – but, you know, what you could do is have a tax increase one day and introduce a new program the other, and the revenue from one cancels out the expense from the other. It's easily done. If Alberta is truly committed to leadership in health reform and improving quality of life, this is one very, very simple, obvious strategy you could take, which even has the support of Mazankowski and was promoted in that particular document as well.

Mr. Olson: Thanks.

The Chair: Thank you very much. Did you want to supplement that?

Ms Olsen: I just wanted to comment on Dr. Sherman's question about we're reaching sort of the hard-core, addicted smokers, and I think we need all of the comprehensive approach. One initiative that I was involved with was with a physician's office, and we actually had a respiratory therapist. The physician identified people that were over the age of 45 and were smokers but weren't showing any health signs of COPD or anything like that. They actually then saw the respiratory therapist, who did a spirometry test. We found that over 50 per cent of those people that we identified needed to go on for further lung function studies, yet they weren't showing any symptoms. I think that's the challenge with the addicted people that we're at right now. We need to have more opportunities to intervene with them, so the work that's being done through the primary care networks and the stronger interest by the physicians in cessation supports and training and more identifying.

From a policy perspective I think, certainly, within the province it would be much better for us if anybody that was admitted to a facility, one of the questions that was always asked is, "Are you a smoker; do you use tobacco?" and then offered some support services while they're in the facility. The other thing that could be done is to add some more amendments to the legislation and designate our facilities across the province as totally tobacco-free facilities and grounds, sort of that leadership role.

So there are some things that would add to what already is being done, but it has to be a comprehensive package.

The Chair: Thank you very much. I wanted to thank all of you for appearing before the committee, and I'm sorry that the time is short. It's a very interesting presentation and discussion and very much appreciated, so thank you for your time today.

Just for the committee members, then. I haven't been advised of any other business. Is there further business?

If not, just to notify you that the next meeting is Monday, November 24, from 5:45 to 7:15 p.m.

I'd like to thank everyone for your participation today, and thank you to the clerk for all of the organization involved in putting this meeting together. It was considerable, so thank you very much, Erin.

Motion to adjourn? Lots of volunteers. Mr. Olson. Discussion? Those in favour? Thank you.

Good day, ladies and gentlemen.

[The committee adjourned at 11:02 a.m.]

Published under the Authority of the Speaker of the Legislative Assembly of Alberta