Standing Committee on the Alberta Heritage Savings Trust Fund Act

1:01 p.m.
[Chairman: Mr. Dunford]

THE CHAIRMAN: Okay. It's 1:01, so we'll call the meeting to order. I'd like to welcome this afternoon the Minister of Health, the Hon. Shirley McClellan. What we'd like you to do, Madam Minister, is introduce the folks that you have with you and then perhaps make some opening comments. We hope that you'll restrict them to under 15 minutes. When the questions begin, we'll start with the opposition members and then to the government members. We'll just alternate back and forth. We will adjourn whenever we reach two hours or the questions end, whichever first occurs. The members are familiar with the mandate of our committee: to review the '94-95 report of the heritage savings trust fund. Members can be assured that if they're wanting to question on any of the recent events, I will certainly be hopping in. So with that, if you'll introduce your friends with you, Shirley, we'll get started.

MRS. McCLELLAN: Okay. Thank you, Mr. Chairman. Good afternoon, members of the committee. I want to introduce to you Dr. Jean-Michel Turc, who is the chief executive officer of the Alberta Cancer Board, sitting immediately to my left. Next to him is Dr. Heather Bryant. She's the director of the division of epidemiology prevention and science at the Alberta Cancer Board. Dr. Bryant is also the director of screen tests in Alberta's breast cancer screening program. Both of these people are known to the committee members, I think. Drs. Turc and Bryant will be pleased to answer any questions that you have on overall program and future priorities. Also with me to my right is Judy Barlow, a lady you may not have met. Judy is the manager of health research with Alberta Health and certainly would be prepared to discuss anything of an administrative nature.

I want to begin by saying that 90 percent of cancer treatments are experimental; only 10 percent are proven. The esteemed doctors to my left may have further comments on this. The need for continued research I think is obvious, given those comments. Cancer remains the number two killer in our province, and reducing the cancer incidence is certainly a health priority in this province. Research, particularly Alberta-based research, is key in achieving that goal.

On a more positive note treatment of childhood cancers has improved dramatically on the basis of research findings. We were very pleased to take part in a research day at the university where we met the Nobel laureate, Dr. Elion, if I pronounced her name properly, who was one of the researchers many years ago who began the work which has led to aggressive treatment of childhood leukemia. After hearing the Nobel prize winner's discourse on this area, I certainly felt very rejuvenated and hopeful of the possibilities that exist. We are certainly hopeful we can make similar inroads in combating the disease among all age groups and in all its forms.

Although we're here today to talk about the 1994-95 expenditures, I want to remind the committee that funding for the applied cancer research program was transferred from the heritage fund to Alberta Health in 1995-96. A research plan was presented to the Alberta Science and Research Authority, and that plan outlines the future intentions for the program.

In the past one of the concerns has been the inability to provide longer term stable funding. This has caused us recruitment problems as well as others, and I know that at the last appearance before this committee we discussed that issue quite extensively. Alberta Health is committed to providing long-term funding to cancer research, and we hope that commitment will aid us in our recruitment efforts.

The '94-95 budget was $2.8 million. That included a carryover of $38,000 from the previous year. Of that, $2.5 million was expended, which leaves us with a carryover of $254,000 this year. The carryover will be used to establish a provincial embryonic stem cell targeted mutation facility. I know you will all want to know more about that, and my two colleagues here will certainly be happy to discuss that with you. Even though it is in this year, I think it's of interest to you.

The funding last year was allocated among five categories: theme-oriented group projects, $1,061,453; multi-user and interdisciplinary facilities and programs, $650,447; commercialization of technologies resulting from cancer research, $143,620; and clinical trials, $378,623. Administration costs for the program were $166,820.

Among the activities planned for the future is a provincial cancer clinical trials network. This would enable the Cancer Board in partnership with the regional health authorities to reorganize and expand its clinical trials to include all cancer patients in the province rather than just those who are treated in Alberta Cancer Board clinics. The Alberta Cancer Board also is hopeful of establishing an endowment. They are committed to raising funds in that area themselves, and a request has been forwarded by them to the Alberta Science and Research Authority for this endowment.

Since this is likely our last appearance before this committee in regards to this program as it does not any longer receive funding from your committee, I want to thank all the committee members, Mr. Chairman, for their support. I think it has been very supportive to cancer research. There have been very good questions, comments, and suggestions raised. I think you can all be proud that the Alberta heritage savings trust fund has helped to establish Alberta as a leader in many areas of cancer research. Most importantly, it has funded important work which will transfer into better health for Albertans. Again, I want to express my thanks at this time to the committee and to the trust fund for their support of cancer research. We look forward to your questions.

Thank you, Mr. Chairman. I managed to stay under 15 minutes. It's not question period now.

THE CHAIRMAN: Well, that's right. It's not question period. There's a large distinction. The Speaker insists on a main question and two supplementaries that tie to this. However, we as committee members agreed this morning that when it's a member's turn, they have the opportunity to ask three questions, none of which may be related to each other, but all should be related to the reason that you're here. So with that we'll begin.

MRS. McCLELLAN: Mr. Chairman, I'm sorry. I apologize. I missed one introduction. I should have acknowledged MLA Yvonne Fritz, who is the chairman of the Alberta Breast Screening Policy Council, and thanked her for her attendance.

MRS. FRITZ: Thank you, Madam Minister.

THE CHAIRMAN: All right.
Howard Sapers to begin, please.

MR. SAPERS: Thank you, Mr. Chairman. Madam Minister, guests, thanks for appearing in front of the committee again. I have a number of questions. To start off, taking the lead from your introductory comments about the cancer-related programming, recently the minister and I and a few hundred other people attended the health expo. I think you'll recall that event in Edmonton. During

the questions, right after your remarks, one member of the audience asked you about the future of the Cancer Board. In your comments there was an indication that as a result of regionalization activities, the future of the Cancer Board was somewhat in question, that there would be an integration of programs, certainly a transfer of dollars. I'm trying to recall the exact words you used, but I believe it was that there would be a total integration. I think that was the way it was phrased. I'm wondering if you could elaborate on that and let the committee know what implications this might have for the close to $60 million that's been transferred to the Cancer Board and what the future may hold in terms of Cancer Board authority and responsibility.

1:11

MRS. McCLELLAN: I'm glad you asked for a clarification. We discussed both the Alberta Cancer Board and the Alberta Mental Health Board in the answer to that question. At that time I said that the Alberta Mental Health Board would cease to exist in the near future and be fully integrated with the regions.

The Cancer Board. I said that there was no final decision on the Alberta Cancer Board itself as to whether it would be maintained. I did mention that cancer is one of the leading killers in our province, that we have felt that it was important to maintain a focus on that but that the Cancer Board was integrating their programs into the regional structure and indeed have been delivering programs in a regional way in the past short years and have continued this year to work more closely with the regional health authorities to ensure that they can deliver these programs outside of the two major centres and certainly make it better for people who are needing treatment. But there has been no decision made as to whether the Cancer Board will maintain its provincial focus. I would indicate again, because of the seriousness of the rise in this illness, that we have felt it important to keep the Cancer Board in place, quite differently than our decision on the Mental Health Board, which was to be a short-term board to co-ordinate the programs and move those into a regional structure immediately.

I think we'll continue to monitor this. The Cancer Board has operated very well, has brought a lot of research into this province, has, I think, helped to deal more effectively with treatment around the province. That focus, I believe, has been quite important to this date and may continue for some time into the future, but that will be a decision that's made.

MR. SAPERS: You recall last year when we met that we discussed the tentative business plans that the regional health authorities had submitted to you. A year has passed. I have had a chance to review many of the business plans from the regions, and it is not clear in those business plans the direction of their programming and how the dollars that have come from the Cancer Board have been integrated. I'm wondering whether or not there is a process by which the regional authority business plans are vetted or filtered through the Cancer Board to ensure that integration. Where might we expect to see the results of that process, if it exists? It isn't apparent in the business plans for the regions.

MRS. McCLELLAN: The vetting of the business plans. Of course the Cancer Board's business plan is presented as well as the regional health authorities'. As you know, last year was their first year, so really what you have reviewed was their first year's business plan. I would expect we normally would have the new business plans in in December. We have delayed that to January. We've made some decisions that we felt were important. We did tell the regions some weeks ago that they would probably not be asked to have their business plans in till January. For obvious reasons we didn't want them to prepare a business plan – it's a lot of work – and then have them reworked when our final decisions were made. I believe that in this round of business plans you will be able to see far more clearly how that is working, because the Cancer Board has been working with the regional health authorities on the integration of their programs and how they can deliver them better. I've made a note that that should be highlighted. I think what you will see, though, is more of a program area, because one of the values of regionalization and integration is that you can use some existing services and not have to duplicate those areas. So there may be costs associated with the program that are in the general cost of the region but specific dollars that are there for a particular treatment, such as chemotherapy, which is developed regionally.

MR. SAPERS: Thank you. I'd like to ask my third question about the screen test program. Madam Minister, Dr. Bryant, there has been some discussion and even some controversy about the screen test program for a number of reasons. One of the things we discussed last year and which again doesn't appear to have been fully resolved in the 12 months since the establishment of the two urban-based programs and what has been expressed to me as a lack of any real evaluation of the outcomes of the products of the programs in Calgary and Edmonton. Now, I know that there's been an interim announcement about breast health for women since then, and there's a parallel process in place. But in Dr. Bryant's answer last year to the committee there was a suggestion that there would be a stronger evaluation component built into not just the urban programs but also the mobile screen test program. I'm wondering if we could be brought up to date on what that evaluation process is and what it's taught us.

DR. BRYANT: I think that in responding to this question, it's important to be clear about the difference between the screening program and screening that goes on in the province of Alberta. Within the screening program itself – and there are two sites, one each in Edmonton and Calgary, as well as the mobile screening program – there actually is already a fairly strong evaluation process. We would be able to give you data, for example, on the number of cancers detected through that process, how they compare with international standards, the number of women reached, and so on. Those are some of the important types of questions you need to be able to answer. Another important question is the number of women referred out for further tests and so on.

The difficulty is that within Alberta so far we don't have all screening going on in an organized programmatic context. For example, if a letter of invitation is sent to a woman in Edmonton and she doesn't appear for screening, it's just as likely that she's having mammograms elsewhere as it is that she's not appearing for screening anywhere at all, and until we are able to get programmatic screening for all screening that goes on, we can't apply the same kind of evaluation throughout the province. The idea of going towards programmatic screening throughout the province was agreed to by the task force report, and you have the chair here of the policy council that is the child of that task force report. But I think it's fair to say that the intention is to move all screening going on within the province in that programmatic context to allow that evaluation.

THE CHAIRMAN: Okay. Thank you.
Howard, you're okay?

MR. SAPERS: That was my three. I'd be happy to continue, Mr. Chairman.

THE CHAIRMAN: No. I saw a look of confusion come across your face. Was it just a quick explanation you needed?

MR. HAVELOCK: It's actually a normal state.

MR. SAPERS: Thank you.

THE CHAIRMAN: I meant that generously.

MR. SAPERS: I know you did, Mr. Chairman, and it's a tribute to your powers of observation.

Well, I do have a supplementary question, but it's on the screening answer, and I'd be happy to come back to it later.

THE CHAIRMAN: Okay. All right.

Paul Langevin.

MR. LANGEVIN: Yes. Madam Minister, over the last 18 years roughly we've spent about $55 million in cancer research, and about $2.8 million, I understand, was contributed last year. It states in the report here that that money was used on 28 different projects that were funded. Are these projects carried on at the cancer clinic or university or throughout the province? Are they restricted to certain areas? Do we also carry on some projects in conjunction with other provinces where we would expend some dollars in co-operation with others?

MRS. McCLELLAN: Was that one question? You wanted to know: of the $2.8 million, how much was spent in Alberta? Paul, is that correct?

MR. LANGEVIN: Yeah. I'd like to know if it was all spent here or if we spent some in co-operation with other provinces.

1:21

MRS. McCLELLAN: Well, I think it would be helpful if we just had Dr. Turc talk about some of the clinical trials and prevention programs we've had in '94-95, like the pediatric oncology group. You might as well hear it directly from Dr. Turc, who is the expert. He could also, if he wouldn't mind, just explain how we interact with other provinces and other countries in cancer research.

DR. TURC: I would be pleased to do so. There's $2.8 million dollars allocated to scientists who are in Alberta. So they work in Alberta. There have been some cases where someone has been for three months or six months on sabbatical in a laboratory in the States and has been taking his grants and coming back to the province to continue to work on the original project, but overall the money is spent in the province. That does not mean that the subject of investigation is only restricted to cancer research in Alberta. Any researcher in the province, as long as his focus of concern is cancer, is eligible to receive the money. So you do not have to have your laboratory based at the Cross Cancer Institute or at the Tom Baker cancer centre. You might be at the University of Lethbridge or the University of Alberta or the University of Calgary, and indeed these latter two universities certainly receive some funds from the Cancer Board to carry on the cancer research.

Now, some of our researchers – and this has just been alluded to by the Minister – are involved in national or international projects. The pediatric oncology group, for example, is a group based in the United States. The radiation oncology clinical trial group is based in the United States. The National Cancer Institute of Canada clinical trial is based in Canada in Kingston. All these groups are supported indirectly by the Cancer Board through the money allocated by your committee for cancer research. For example, we will have an investigator here who is also the prime investigator on one of the U.S. protocols. Indeed, we have two or three such investigators in Edmonton who are the leading investigators for an international protocol. We are supporting part of the research which has been done here. We are supporting the infrastructure for data management but contribute to the overall good of cancer research on an international research project.

We are also interacting quite closely with all the national granting agencies in Canada and the national granting agencies in the United States involved in cancer research. In Canada it would be mainly MRC, the Medical Research Council, and the National Cancer Institute of Canada, and in the United States it would be the National Institutes of Health and the National Cancer Institute. So we are working in close co-ordination with these different bodies. In fact we have some of our own people sitting on some of the committees or boards of these organizations to make sure that at all times we know what's happening. Furthermore, I should add that one member of ACOR, the advisory committee on cancer research, that is made up of seven scientists all from outside the province advising the board on the quality of cancer research and new directions for cancer research, is now a member of . . . Help me, as I'm lost, with the name of the committee of the Heritage Foundation for Medical Research.

DR. BRYANT: The health research advisory council?

DR. TURC: No. No. The one with Dr. Fuks from Montreal.

DR. BRYANT: I can't help you.

DR. TURC: I think it's the Scientific Advisory Council of the Alberta Heritage Foundation for Medical Research. The chairman of ACOR – I forget his name.

DR. BRYANT: Ron Buick.

DR. TURC: Ron Buick from Toronto has been invited also as an ex officio member to attend the meeting of the Alberta Heritage Foundation for Medical Research.

So these are ways that we are following to make sure that we are informed of the initiatives and efforts of the other agencies, and we are trying to co-ordinate cancer research.

MR. LANGEVIN: Thank you.

THE CHAIRMAN: Third question.

MR. LANGEVIN: Yes. Thank you, Mr. Chairman. I was interested in the minister's statement that 10 percent of the cancer treatments are proven treatments and that about 90 percent are on an experimental basis. I was wondering about the experimental basis: how wide a scope do you look at? Do you look at unortho-dox medicine like interaction with DMSO treatment or chelation treatment in relation to cancer?

DR. TURC: This is a very interesting question and a very difficult one. Three years ago my answer would have been: absolutely not. Today I have to tell you that we believe our role might not be to provide alternative therapy but to provide patients with all the information they require and need to make a decision. In the end it's their decision. Three years ago it would have been very difficult to find anyone at the Cross informed enough or willing to provide information on alternative treatment. Now we are initiating a program to inform all the nurses and physicians on some of the

alternative therapy available: where do you go to get more information, and what is known objectively about these different therapies? In fact, there has been a small booklet which was published in Ontario by a breast research group, a breast information pilot project. It's a 200-page booklet, very well done, with a catalogue of all the alternative therapy. What do we know? Where do you go for it? Where do you phone? What kind of additional information? I think that definitely will be a part now of our mandate and our duty: inform the patients and allow them to make the decision.

THE CHAIRMAN: Thank you.
Debby Carlson.

MS CARLSON: Thank you, Mr. Chairman. My first question is for Dr. Bryant. A moment ago you said that it's just as likely that a mammogram is being done elsewhere if a woman doesn't respond to the invitation letter. Can you tell us how you would know that?

DR. BRYANT: We know that in Alberta there are probably about 30,000 women served by the screening program. There are about 15,000 to 16,000 women seen a year, and the majority of those are on a two-year schedule. We also know that there are probably about 30,000 screening mammograms done in the target age group in fee-for-service clinics, but we really can't say that for sure because we don't know which of those are for diagnosis and which are for screening.

The statement that women may be going for screening elsewhere or may not be coming in comes from a study that we did where we actually sent a card to women who didn't respond to the letters of invitation and just asked them why they didn't come in for screening and said, you know, that there may be a number of reasons why they chose not to respond to the letter. Of the relatively small proportion of women who responded to that card, the commonest reason was that they were already having mammograms elsewhere.

MS CARLSON: Is there any attempt now to co-ordinate that information and monitor it on a long-term basis between yourselves and the fee-for-service clinics?

DR. BRYANT: Certainly that would be one of the objectives of moving towards programmatic screening throughout the province. It's one of the very important questions that has to be answered, yes.

MS CARLSON: Is there a time line on that?

DR. BRYANT: The time line for the policy council is to have it in place by the 1st of April 1997.

MS CARLSON: Okay.

THE CHAIRMAN: All right.
Victor Doerksen.

MR. DOERKSEN: Can you tell me what the process is or what role the Cancer Board plays with respect to reviewing research that happens around the globe on cancer and how we might implement whatever advances have been made? Do you follow the question?

DR. TURC: Yes.

MRS. McCLELLAN: Do you want to take that, Dr. Turc?

DR. TURC: For a scientist to stay at the leading edge, it is his duty and responsibility to be fully informed of what's happening. You get informed mainly through two different kinds of activity. The first one is reading the specialty publications and journals, which are generally published once a month, sometimes a little more often, which will bring you up to date with what's happening in your field.

1:31

The second opportunity is really national or international meetings where you are able to find all the people who are basically working on the same subject as you are, or a subject very close to your interest, and are able to share knowledge and experience. It was following such a meeting, for example, that scientists at the Cross had established collaboration with a group in Phoenix, in California, in Florida, in the Netherlands, in the U.K., so there is really a very vast network. I have to say that I myself, personally, am using the Internet a lot to find out what's happening. It's incredible the amount of up-to-date scientific information that you can find on the Internet. That's what we will be using.

Another thing is that our body is relying heavily on the advice of the seven members of the Advisory Committee on Research. We not only are making the selection and reviewing ourselves the proposals that they receive from people who want to do cancer research in this province, but also twice a year we meet with members of a research committee on our board and advise the board on, you know, what are you doing well, what are the important things you are missing in your attempt to control the disease, and what are the new orientations that really Alberta is very well fitted to be successful at and to make some major progress on. So I would say that we will be relying on this different expertise and sources of information to make intelligent decisions.

THE CHAIRMAN: Okay. Before we go to your next question, we have some visitors in the gallery. I'd just like to point out that what you're witnessing today is the hearings of the Standing Committee on the Alberta Heritage Savings Trust Fund Act. We have in front of us today the Hon. Shirley McClellan, the Minister of Health, and some of her associates. The questions today are coming from the people in the front row, who are part of the opposition Liberal Party, and the people in the second row, who are part of the government Progressive Conservative Party. We are not required to sit in our own designated desks at these particular hearings, so people are free to move around and also to remove jackets if they wish. So we're glad you're here to help witness this very significant event, and we'll now proceed with the questions.

MR. DOERKSEN: To follow up on that, how do we get from the research which shows some evidence to putting it into policy or into practice?

DR. TURC: That's a whole area of translational research. How do you go from the bench in the laboratory to the bedside? This is really an area where our board is unique. Most of the research institutes will be focusing on purely basic research or totally applied research. I think in the Cancer Board we have the ideal setting to have really a representation of both basic science and chemical science.

One of the tools that we are using for that – and I think it's very much part of the accountability concern, if you want, of our board and the trustees who are working with the Cancer Board. We have an obligation, a duty, to ensure that scientists – and I'm talking now mainly about basic science, because that's where you will find the natural behaviour and disease to try to isolate yourself in the ivory tower – understand that they also have a social responsibility. We

have the responsibility to support their research. In return they have the responsibility to disclose the product of their research to us and for us not to do the translation, because we do not have the knowledge or the power to do it, but to facilitate the translation. I don't think you will find a lot of research budgets where you will have some money allocated for technology transfer.

We believe that it's our duty to make sure that whether it's basic research or applied research or clinical research, people have the tools to make sure that it will be used not only for the two or five patients who might benefit initially the first year at the Cross or at the Baker but maybe all the patients of western Canada or Canada initially. So that's part of, if you want, the administration of the board: to facilitate and, as part of the culture of the organization, to make sure everyone understands that it's part of our social responsibility. The setting is ideal because the Cross in Edmonton and the Baker in Calgary are also very unique in the fact that you have under the same roof a research laboratory and patients. So people have to start to talk to each other.

We had a visitor come from Ottawa looking for a job – you know, there are some people coming from outside looking for jobs here – and spending about two days here. He made his presentation, and he told me after his two-day meeting, "You know, the most exciting thing about the work that you are doing here and coming to Edmonton was that when I made my presentation, there were not only clinicians, because I was expecting to find clinicians, but I found a lot in basic science who came to see me, and we started to discuss about possible ideas for a corporation and joint projects that we will be able to do." He does not have that in Ottawa. So I think that's a very unique feature of the Cross here.

MR. DOERKSEN: As part of the social responsibility does that also include, then, public education, for instance, on the dangerous effects of smoking? Is that part of the role of the Cancer Board as well?

DR. TURC: The Cancer Board has also a role in public education, and I have to say that it's probably not a role we have been doing very well at in the past. We have not been focusing a lot of energy and time in trying to educate people. One of the reasons is that we know very little about the behaviour of patients, their families, or the public at large. I'm sure you're aware of the tremendous difficulties that we are having in trying to have the population at large, the young people in particular, understand why smoking is bad. I think everyone understands that smoking is dangerous. The problem is to find a way to deliver the message which will make that individual receiving the message change their behaviour. We have not done a very good job. In fact, some research now is starting to be done on the role of behavioral research, but that's done in Calgary.

MR. DOERKSEN: Okay. Thank you.

MRS. McCLELLAN: If I can just add. One of the areas where I believe we will have greater success in some of this area is through the regional health authorities, who have a strong mandate for a prevention and wellness program. Through their public health section, which we looked on as health units in the past, I believe there's a lot of opportunity for a very close working relationship in the areas of prevention and promotion. Obviously the Canadian Cancer Society has really been the vehicle that we have used more in Canada for education on prevention.

I think it is important that the information you learn from genetic studies, from family history studies, and so on, be passed through to the public as well, as indicators are there for certain types of cancers. I certainly believe that the regional health authorities would be a vehicle that should be used very aggressively to carry that message. They're also well positioned to know whether these are problem areas. It will be in some areas and not in others, so we're very hopeful that we'll see that moving forward with the integration of the some of the programs that are going to happen through the regions.

Mr. Chairman, I wanted to just raise one other comment in response to Debby's comment on screening and diagnostic mammograms. Are we on a first name basis here? Is that okay?

1:41

THE CHAIRMAN: Yes.

MRS. McCLELLAN: He hadn't called me to order yet anyway.

One of the areas that is really frustrating to researchers is access to information. We're all very conscious of the need for privacy on personal health information, but through the use of technology we believe that we will be able to utilize information that's important and still protect privacy. The name of the individual is not what's important; it's some of the other information that's related. As you know, we're looking very seriously at what types of technology can do this best so that researchers can access that information and still protect the privacy of the individual. It's very frustrating to know that we have so many mammographies that are happening in the province, but we can't really tell the Cancer Board whether they're screening or diagnostic. We need to know that information, and certainly the council is looking at that area.

Thanks, Mr. Chairman.

THE CHAIRMAN: Okay.

Mike Percy.

DR. PERCY: Thank you, Mr. Chairman. Madam Minister and associates, my question relates to the integration of some of the work done by the Cancer Board with the regional health authorities. Given that the regional health authorities live day by day, and all things being equal they will allocate funds to dealing with acute care crises that face them presently, how would research be able to sustain itself in that environment? Are the funds going to be earmarked? Is there some mechanism for ensuring continuity of funding of programs? I mean, what's the nature of the transfer that allows, then, the unique contribution of the Alberta Cancer Board to persist?

MRS. McCLELLAN: We're talking about more than research when we talk about integration with the regional health authorities. A large part of what the Alberta Cancer Board does is direct treatment in the province. So, one, keeping with our belief that people should have access to health services as much as possible close to the region that they live or in the region, that will expand. Certainly there has to be some tie to that with research. You wouldn't want to lose that information, but there is absolutely no reason that the Cancer Board would lose that research by getting involved with the regional health authorities on a research basis. In fact, this is meant to enhance them. That's what we were talking about when we were talking about their programs being integrated, and I apologize if I confused you. We're not looking at taking the $2.8 million and distributing it to the regions. We are moving many of the cancer programs which are tied to research information that can be gained and co-operating on some research, clinical trials, et cetera in the regions.

Dr. Turc or Heather might want to mention a little bit more on that.

DR. TURC: I will be pleased to do so. The base for research is all our clinical activities, and at the same time the base for our clinical

activity is research. It is very difficult for the Cancer Board to decide which one is the most important. At the end of the day if you remove research, there is really very little justification for the Cancer Board. The justification for the Cancer Board is the co-ordination of the experimental treatment that we are providing.

The minister did indicate that our role and our mandate now is to try to decentralize care as much as possible. You know that amongst all the care provided, only 10 percent is known. We have standards, we know what to do, and there is no discussion. All the rest is variable. We do not treat breast cancer today the same way as six months ago. That is information that we can transfer to the region by having, if you want, some of our agents – like we have Cancer Board people in Fort McMurray or in Grande Prairie or in Lethbridge and Medicine Hat. We want to extend the network of expert knowledge for treatment of cancer across the province, but in return we want to make sure that the information which has been provided by the patient treated in Edmonton or in Calgary will not be lost. If these patients now are getting treatment in Bonnyville or in Hinton or in Banff instead of in Edmonton and Calgary, we want to make sure that the information will come back to the researchers at the Cancer Board.

That's why one of our research projects for the coming year is that at the same time we extend the network of clinical expertise across the province, we want also in each region, or maybe shared between two regions, a small nucleus of data management expertise, people who will be able to follow the clinical trial to make sure that there is compliance with the trial and to make sure that in fact the people who are getting treatment will be able to contribute to the advancement of our knowledge of the treatment of cancer.

DR. PERCY: I'd just like to follow up, and this is in the context of outcomes and assessing the Alberta Cancer Board. It is my understanding, though, that when you look at teaching hospitals that are research oriented, concentration within those hospitals is really essential to maintain their accreditation, to ensure that they capture other sources of funding, and for their ability to attract scholars for research. You don't see, then, this shifting of some of the program activities to the other regional health authorities being to the detriment of the high levels of excellence that have been achieved in the two major teaching hospitals in the province today.

MRS. McCLELLAN: Unfortunately, I have to say that the incidence of cancer is growing at such a rate that we are not short of clinical opportunities, and we say that with regret. I don't think that anywhere would it be suggested that at the expense of a person's own quality of life we would say that we value that they would be in a concentrated research area more than their own personal health and quality of health. I think that's why Dr. Turc was referring to the interaction between clinical trials and research. It's very difficult to say which is more important; they're both important. But you have to think that if somebody does live in Bonnyville or High Level and they have to live in Edmonton or Calgary for a period of treatment that could well be delivered in their own community, you would certainly have that preference, because there's a great deal of cost attached to that. Although we do pay for cancer drugs, et cetera, this is very difficult.

You also know that in health treatment of any kind, the home, the family support, and the support of other people are extremely important. I believe that by having a data management expertise develop, we can include that information from people who are recipients of care outside of the two major centres and make sure that that information is there for researchers. It may even improve some of the information that we get by having the families involved in it, which is not as easily done if they have to live in one of the two major centres.

THE CHAIRMAN: Okay. Before we go to your third question, Mike, it would appear that we have a number of young visitors this afternoon. It would appear to be a group from a school. Is that correct, and from what school?

UNIDENTIFIED SPEAKER: They're from McKernan school in Strathcona.

THE CHAIRMAN: Oh. Well, welcome to you. What you're witnessing today is a hearing of the Alberta heritage savings trust fund. For those of you that can see the front row here on my left, Shirley McClellan, who is the Minister of Health, is appearing before us this afternoon. The distinguished-looking folks on my right in the first row are from the opposition Liberal Party and in the second row the government members, the Progressive Conservatives. They are here questioning the minister today about applied cancer research. So we're glad that you could join us and hope you find this of some interest.

Michael, your third question.

1:51

DR. PERCY: Thank you. Abstracting, then, from the issue of treatment, which I think can be decentralized, I know from discussions – because a number of my constituents teach at the university, are involved in some of the programs – and I know from talking to colleagues in Calgary that the research community is very concerned about the sort of dispersal now of the research core that has been built up. In fact, the Cancer Board does come up in this regard: the uncertainty with regards to funding, exactly what's going to be shifted, what core will remain, and the continuity of the program. So in light of the uncertainty both about structure and in terms of funding, I guess the question is: is the Cancer Board still able to attract and hold onto first-class national and international scholars?

MRS. McCLELLAN: Well, I'll answer first, and then Dr. Turc may want to comment on recruitment, because that's his area of expertise. We have held the funding for cancer research stable in this province for some time. Where other areas have faced reductions, it has not. In fact, what we're discussing here today is what we're supplied through the heritage fund. We have made that commitment in our department to cancer research. I mentioned as well that the Cancer Board is looking with great interest at the possibility of an endowment in the province which would allow long-term, sustainable funding for research. We know that that's important.

Dr. Percy, I know that you do have friends at the university who are very knowledgeable about research, and they would tell you how many research dollars have come into Alberta in the last two years, particularly in medical research dollars, not all in cancer. The amount of dollars that have come into Alberta is extremely significant, one, because of the university's efforts – and I think we have to give Dr. Tyrrell, Martha Piper, and others at the University of Alberta as well as Dr. Smith at the University of Calgary a great deal of credit for that environment.

I think they would also say that a number of the initiatives that this province has taken in the last two years have also made it an extremely attractive place for companies to invest research dollars. They do see stability that can be gained by having a sound financial basis for operations. You also know that the University of Alberta and University of Calgary have a very aggressive research target to reach. I'm sorry that I didn't bring you the exact number of health

research dollars, a lot of it in pharmaceuticals I will grant you, that have come into this province in the last two years. It is extremely significant. So I believe that researchers look at Alberta as a place in Canada that is a place to live and to invest.

I would also remind you that we've had the Heritage Foundation for Medical Research, which is world renowned and not just nationally, in our province, which has a very high success level of projects and is a very stable and sound foundation in the province, which helps attract researchers.

You might want to just talk about the importance of stable funding for recruitment.

DR. TURC: I think that has been one of the major accomplishments this year. The $2.8 million that we have been getting for the last 10 years, basically since 1987, I believe, when it became $2.8 million, was approved sometimes on a year-to-year basis, sometimes for two years, sometimes for three years but with absolutely no road map for the future. As a result it has been impossible to recruit with the assistance of this $2.8 million a good researcher who will agree to come to this province to do research. Now, with the support being provided through the channel of the budget of Alberta Health, we consider the $2.8 million to be permanent and to be part of our base for activities. Rightly or wrongly we see that as a permanent fixture of our activities, and it is starting now to give us really more freedom to be able to plan on a long-term basis.

I should tell you that we have recruited in the recent past one of the leading radiobiologists from the M.D. Anderson Foundation in Houston. People are becoming interested. The problem is that we will very quickly become the victim of our own success. The $2.8 million is fine for a small program, but there is pressure coming from Dr. Bryant to have more activity in outcome research. She's just recruiting right now someone to lead the activity in outcome research at the Cross Cancer Institute in Edmonton. There is pressure from her to do more epidemiology and public health related activities. All of that costs money, and the $2.8 million of today will need to be $5 million to $6 million three years from now. That's why the Cancer Board has decided to look at the major endowment for cancer research and has agreed to go also into a major fund-raising program to be able to raise some money.

MRS. McCLELLAN: I should just add to that, and fortunately somebody sitting beside me keeps these figures in her head a lot better than I do. Incidentally, pharmaceutical research is about $12 million a year, and that was one I was referring to.

A good point that Judy has made here is that the Alberta Heritage Foundation for Medical Research attracts $3 for every dollar that it expends, and the Cancer Board attracts a similar return. So $3 for every dollar that we expend in that area – and their research budget overall is about 7 and a half million dollars, not the $2.8 million only that we talk about. Dr. Percy, I know that being an economist, you want to know that we're getting a very good return for those dollars that we are expending.

THE CHAIRMAN: Thank you.
Moe Amery.

MR. AMERY: Thank you, Mr. Chairman. Madam Minister, my question is on the applied heart disease research. I see we haven't given any money to that program since 1982.

THE CHAIRMAN: What page are you on?

MR. AMERY: Page 33. I see that we haven't given any money since 1982. Can you tell me what the status of this program is? Does it still exist, and how is it being funded?

MRS. McCLELLAN: We have heart disease research in the province, but it does not exist in this way anymore. Most of the cardiac research is occurring, I believe, at our university hospitals, where our cardiac programs are. I can't tell you how aggressive it is, but I'll certainly drop you a note through the chairman and let you know that. You will see that next year this program will not be here anymore either, but that will not mean that we don't continue very aggressively with cancer research. Perhaps in some ways moving it, as valuable as the dollars have been through the heritage trust fund, we've been very confined in those amounts. Obviously in departmental budgets you can look at priorization and reallocation of dollars.

Do you know any more about that, Judy?

2:01

MRS. BARLOW: Very briefly, when the Heritage Foundation for Medical Research was established, it was decided to divert the funds that were targeted for heart research to the foundation's budget overall. They made the decision to expend the dollars on personnel support and infrastructure support as opposed to project specific work.

THE CHAIRMAN: Okay.
Howard Sapers.

MR. SAPERS: Thanks. I want to stay with this question of transfer and evaluation. I'm trying to reconcile some of the information from today's answers with some of the answers last year. I understand that we are in a period of evolution. Some would use even harsher terms. But is there in fact a specific evaluative framework that's been developed that will look at the transfer of some clinical and research programs and the responsibility of those programs from the Cancer Board to the regional health authorities and in fact the funding from the heritage savings trust fund to Alberta Health? What I'm looking at are specifically elements that would look at accountability, cost, access, continuity of services and research.

MRS. McCLELLAN: Hon. member, I do hope that you do not go dashing out of here and talk about transferring the research to the regional health authorities. I apologize if I have in some way in my opening comments, by talking about the regionalization of cancer programs and the work that will be done with research associated with those transfers – it is not the intention to transfer the research dollars to the regional health authorities per se.

I'd just remind all of you that a very few short years ago, and in fact even weeks probably in some areas, all of the cancer treatment in Alberta was done in Calgary and Edmonton. In fact, I think probably at one time it was all in Edmonton. I can't remember which was first.

DR. TURC: Edmonton.

MRS. McCLELLAN: Today that is not necessary. You can receive chemotherapy treatment and other treatments in Grande Prairie, in Medicine Hat, and in other areas in this province, and that's very positive. As I indicated to Dr. Percy, you should not expect that people have the extra costs as well as emotional costs of being away from their home and family at a time when they especially need that support. However, neither do we want to lose the information that can be gained through that, and that is where the linkage between

research and programs will occur. The clinical trials research that will occur needs that type of information to ensure you have as broad a cross section as you have.

As I also indicated to Dr. Percy, unfortunately – and I say unfortunately – we are not short of cancer patients and information for research. In fact, it's growing, and there will always be some research or some treatment – I shouldn't say always because at the rate that medical technology is moving, we've been able to do a lot. For example, radiation treatment: the linear accelerators and the equipment that is required around that is extremely expensive. The knowledge to operate those is very select, and it's unlikely in the short term that you will see that expand, at least in the form that it's delivered now, beyond those major centres. But there are a lot of things we can do. Because of the development of the pain gun, I think you call it – I don't know what the technical word for it is, but something that was developed right here in Alberta – people can go home while they're going through treatment and not have to be hospitalized.

So we need to keep the information research opportunities alive as we move out, but we're not, I think, looking at taking the $2.8 million – did I say billion dollars? – out to the regions.

MR. SAPERS: You made Jean-Michel very happy, though.

MRS. McCLELLAN: Yeah, for a moment. When you're discussing what the Cancer Board does – and this is a narrow part of it – and as Dr. Turc said, it's very hard to say which comes first, the chicken or the egg, in this case. Which depends on which? Clinical work and research or research and clinical work? They're so closely tied. So that is not what we're talking about when we talk about the Cancer Board doing more on a regional basis.

Dr. Turc may want to follow up on that.

MR. SAPERS: Perhaps just before he does, I could clarify. I didn't want to interrupt the minister. I didn't misunderstand the application of the $2.8 million and that research, but I was specifically concerned about the fact that there a major change. It's happened sort of at both sides of the question of how we deal with cancer in this province. The dollars for research have been transferred, and controlled, to a department from the foundation, and clinical programming to some extent is being transferred to the regional health authorities. Because of that, I'm concerned that there isn't, from the information that I'm hearing today in some of the answers, really an evaluative framework to look at those two major transfers.

When I said trying to reconcile that with information from last year, I was specifically thinking again of the screen test program, where in Dr. Bryant's comments last year she indicated very strongly that there would be a reliance on regional evaluation or regional health authority based outcomes. So that was really the specific focus of my question.

MRS. McCLELLAN: Uh-huh. Well, I think Dr. Bryant answered your question on the screening program evaluation. That's good. It's the other side that we don't have all the information for.

The Cancer Board is responsible for developing an overall business plan for all the areas that they're responsible for, both in the program as well as in research. The regional health authorities also must develop business plans. The Cancer Board will be working with the regional health authorities on any work that they transfer to the authorities. So if work is occurring in Medicine Hat, that will be taken into account with that region and obviously the area they serve because some of the service areas may transcend even regional boundaries, Howard.

I would remind you also that it is part of the regional health authorities', the Cancer Board's, and the Mental Health Board's responsibility to put an evaluation process into their programs. One of the problems we've had in the past with health expenditures is that we have not required an evaluation, and we are not alone in that. In fact, Alberta was the leader in developing a health systems information management process at a national level. We do expend a lot of dollars in health, and we do need those performance measures, those evaluating measures. We've done a number of things. I know that you're most keen on the work of the Pharmaco-economics Institute, which is another area that we're looking at to evaluate whether we are actually expending our dollars wisely in pharmaceutical utilization.

2:11

One of the difficulties that we have in all of this area is that there isn't a model anywhere that is actually all that great. So we're developing a lot of these models as we move along. I can tell you from my discussions with my colleagues in Canada that we're not behind anyone in this area. In fact, I would say we're in a leadership role in most provinces in Canada in requiring evaluations. We could and we should be pressed to get better in that area.

So they're very good points. It would be nice if we could just order up one that somebody has in a catalogue that says, "This will work for this," but we know there's going to be a bit of trial and development in that area.

MR. SAPERS: I'm happy to hear that it's very much on the agenda, because I think some of the strides that we've made through heritage savings trust fund funding and some of the really world-leading work that the Cancer Board has done – I'm nervous about that momentum being lost with the shifts that are happening.

MRS. McCLELLAN: You think it would be better if the dollars were back with the heritage savings trust fund?

MR. SAPERS: I'm not saying that, Madam Minister.

MRS. McCLELLAN: No. I was just asking a question. Can I ask questions?

THE CHAIRMAN: We're almost getting into a debate. I'm still showing you just at your second question, and we've been at this with you, with all due respect, for . . .

MR. SAPERS: The minister and I just bring that out in one another, Clint.

THE CHAIRMAN: Well, I've been very tolerant, but we're going to have to speed this up. We haven't even got through the first round of questioning, and we've already been here an hour and 15 minutes.

MR. SAPERS: All right. I will move directly to my second question. Thank you, Mr. Chairman.

The minister last year mentioned the importance of accountability and outcome measures. I'm wondering, Madam Minister, perhaps with Mrs. Barlow here with you, if you could let us know what specific research has taken place in this regard that has been funded by heritage savings trust fund money and what the products of that research are, if in fact the research has been completed.

MRS. McCLELLAN: Are you wanting specific projects that have been looked at for evaluations in that area, or are you talking about general evaluation processes? There have been some research projects that have been funded to do an evaluation area.

MR. SAPERS: It's the specifics about accountability structures and development of outcome measures in research that would look at those two issues that I'm interested in.

MRS. McCLELLAN: So we should actually ask Dr. Bryant if she wants to give you a few examples of those. Remember, the funding that we're talking about now is funding that was in the heritage savings trust fund. When we do our budget debates, you'll be talking to me about my departmental work, and we can get into the Alberta Health business plan in that area.

DR. BRYANT: Probably one of the most airtight examples of that kind of evaluative research is the randomized control clinical trials that the Cancer Board is a participant in. In those kinds of trials, instead of just applying a new treatment to an individual and seeing how it works out, it's a randomized process where an individual agrees to be in a study where they will either get a standard treatment or the new treatment under investigation.

Often they're multicentred – some of this comes with funding from outside; some of it was funded primarily through the heritage funds in the past – and very much look at outcome indicators. These outcome indicators could be a number of things. It can be disease-free years without relapse. It can be survival, if it's a very serious form of cancer that they're presenting with. More and more we're moving into the measurement of quality of life as one of the outcome measures. Certainly we're working with the National Cancer Institute and looking at various ways of routinely collecting quality-of-life information on patients.

In terms of the kinds of things that we do on a broader initiative, we're already providing to the regional health authorities cancer statistics on their own RHA so that we can now start working together perhaps to look at some of those initiatives and how we can integrate with their activities and start looking at things on an RHA basis. We don't expect that each RHA is going to choose to do exactly the same things, for example in the area of prevention, but we are hoping through our RHA program to at least have them have a clearing house so they know what's going on in other RHAs so they can get good ideas from others to help them out with evaluation of their programs, if they want to do that, and to provide long-term data to them.

MR. SAPERS: Thanks.

THE CHAIRMAN: Now, believe it or not, I still show you as having one question.

MR. SAPERS: Thank you, Mr. Chairman.

MS CARLSON: The questions are short; the answers are long.

MR. SAPERS: The answers are good.

MRS. McCLELLAN: Oh, I think when you look at it, you'll find the questions are pretty long.

MR. SAPERS: The answers are fine.

THE CHAIRMAN: Hurry; hurry.

MR. SAPERS: I'm just trying to think of the most succinct way to put this, Mr. Chairman, but thank you.

Last year we were advised that when the Cancer Board is involved in funding research, particularly research that ends up moving to industry, the goal is that once the Cancer Board is 100 percent reimbursed for all of its expenses, then roughly a third, a third, and a third would be shared: one-third going back to support of research in the lab; one-third going back to the investigator, which may or may not be a commercial partner; and then one-third going back to support general research at the Cancer Board. I understand that that formula is not always adhered to, and I'm wondering if you could advise us of circumstances when that formula would not be adhered to. What kinds of dollars, perhaps forgone dollars, have there been last year because the Cancer Board received less than what might be its two-thirds share under that formula?

DR. TURC: You are correct; the formula is one-third, one-third, one-third, and there have been some exceptions. The exception which comes to mind is one which was negotiated I believe between a year to 18 months ago, where instead of getting one-third, the investigator is getting 45 percent. I don't have the total equation in front of me, but there is also a duty for the investigator to put some money back either through our Cancer Foundation or through the research laboratory. I can't remember. In one case the deal was better just because the contribution of the investigator was not only unique and outstanding but disproportionate compared to the contribution, for example, of the institution. We are prepared to be flexible within a reasonable limit. When we started to negotiate with this individual, we started at 50-50, and we went down to 45. I don't think we will see the Cancer Board putting on the table anything more than 50-50 in any scenario, but some universities are getting this 50-50. I think we are probably one of the most conservative ones as far as one-third, one-third, one-third: one-third to the researcher, one-third to the Cancer Board, and one-third to the base department of the investigator.

Now, I should point out, Madam Minister, that you can distribute money only if you have revenue, and to do that you need some royalties flowing. The amount of royalties that we had last year was less than $100,000. Maybe one day we will hit the jackpot. Apparently, one out of 25 patents will bring you some money, and we process probably four or five patents a year right now.

2:21

THE CHAIRMAN: Okay. Thank you.
Yvonne Fritz.

MRS. FRITZ: Thank you, Mr. Chairman. My question is just a general question, and it's in regards to outcome of research. I'm thinking that it's appropriate, but I'm not quite sure, so I'll get you to help me out with it. I'm wondering if the research in any way has led or contributed to the development and implementation of a comprehensive set of clinical practice guidelines more on the treatment and care of cancer patients. I can think of a number of areas for clinical practice guidelines in this regard, but the area I'm specifically thinking about is pain management. We know there's a considerable amount of pain for cancer patients, and I'm wondering what would be, for example, the most effective medications, the dosages, the side effects, et cetera, and it could lead from there.

MRS. McCLELLAN: Heather or Dr. Turc, do you want to handle that? I would say the answer is yes, that research does lead to the development of clinical practice guidelines in a number of areas of cancer treatment and probably in pain management too.

DR. BRYANT: Yeah. There are two very active pain management groups at the Cancer Board, one each in Calgary and Edmonton. I think Dr. Bruera's work has already been mentioned here as being very innovative and leading to home-based pain management. Yes, right now it is developing I think what could be called clinical

practice guidelines. In the larger perspective, the Cancer Board's looking towards developing clinical practice models where not only are the guidelines developed, but the information that goes into it about the patient's stage and the information about outcome which comes out of it is monitored on an ongoing basis. So in those cases where we don't have active research projects but have standard therapies that are being used in different ways, we can evaluate those as well.

MRS. FRITZ: So there are clinical practice guidelines in place that are standardized and being utilized?

DR. BRYANT: There are some, but they are very specific to the patient needs and the type of cancer that the patient presents and the types of pain and their own sensitivity to drugs. So it's very difficult in that particular area to be very explicit with clinical practice guidelines. It's often a matter of working with the patient.

MRS. FRITZ: So it may include psychological, social, or spiritual help for the patient. Or are they just very specific in regards to medicine?

DR. BRYANT: Excellent question. Most clinical practice guidelines don't actually look at provision of those, although most treatment very much does look at incorporating psychosocial needs of the patient. Certainly that's provided at the cancer centres and at affiliated centres. Whether there could ever be clinical practice guidelines developed in that area I don't know, but I know that certainly the psychosocial group is collecting information on quality-of-life outcomes for those that they counsel so they can help build those in.

MRS. FRITZ: My third question, Mr. Chairman, is in regards to strategies, whether there have been any strategies developed to enhance the continuing medical education, I think, of physicians, back to what I was discussing earlier, with the clinical practice guidelines.

MRS. McCLELLAN: Are you referring to students in medical schools or ongoing for physicians who are practising?

MRS. FRITZ: Yes. Both.

MRS. McCLELLAN: Obviously it is a part of the program studies in the medical schools, and there are opportunities for physicians who are practising and have been practising. You may not be aware that it is not a requirement for physicians to upgrade their education to retain their licences at this time, but the College of Physicians and Surgeons is certainly looking at this area and saying, you know, we should really be reviewing these matters. Most physicians voluntarily upgrade their medical education either through courses that are now available for people by distance learning or coming to seminars – but it's very difficult – or from reading journals and publications on a number of different areas.

Dr. Turc might want to comment on the opportunity for physicians to become aware of new treatments other than through journals and publications, whether there are seminars available and how well they are attended.

[Mr. Doerksen in the Chair]

DR. TURC: There are indeed seminars available. Just for example, I offer breast screening in cancer of the breast. I'm aware over the last two or three years in Edmonton of at least three seminars which were totally dedicated to that subject, where we are trying basically to provide the latest up-to-date information not only to the general practitioner but also to the surgeon. It is the Cancer Board's intent probably at the end of March or April to organize also a one- to two-day conference, if you want, for cancer care in Alberta – and we want to make that a yearly event – where half of the session will be dedicated really to the people working in the region and the other half to the physician. So we are trying, really, to find tools to make sure that people have access. The GPs in the small towns will have more and more responsibility, and it is our duty to ensure that they have the tools, that they can learn the tools, and that they will be able to use the tools properly to treat their patients.

MRS. FRITZ: Thank you.

MRS. McCLELLAN: I would expect also that with the very nature of a physician's work, many times one physician will come and attend a seminar and go back and take the information to their colleagues, because it's very difficult for all physicians to leave an area and leave their patients without care. So I think that occurs, particularly in the regional bases where they can send one, two, or three, whatever the proper number is, and then they go back and share the information again.

MRS. FRITZ: Thank you, Mr. Chairman.

MR. DALLA-LONGA: I guess my question is mainly to Dr. Turc. If you had more money, what other things would you do? What other programs, what other services do you feel would be necessary or feel are worth while? What other programs would you carry out if you had more money?

DR. TURC: You are talking about research here?

MR. DALLA-LONGA: Sorry. Yeah.

DR. TURC: One of the major developments in the last two years in cancer research has been the whole aspect around the genetics of cancer. For example, you are aware of the mapping of the genome, which is an international joint venture between western Europe, the United States, and Canada, where the responsibility for mapping and finding the chromosomes where the gene of a particular disease is located has been distributed between different groups. So you are aware that there are now several genes which have been identified, for example, for breast cancer. The question is: first, what do we do with the detection of these genes? How fast can we implement that? Second, when we find someone with the gene, what do we do? What kind of advice, if any, can we give the possible future patient? Is there any implication? So the whole aspect of genetics and diagnostic and screening is very important.

The second aspect is that it is known now that cancer is basically a dysfunction of a certain gene or genes, and we want to embark on a major program of gene therapy: how to manipulate the gene of an individual and how to make the gene which was evaluated as abnormal or deficient normal again to be able to control the disease. I should point out that such a program started at the Toronto general hospital about six months ago now with very few cases. There is a program which will be starting soon probably in Vancouver. Those are the only two programs in Canada.

If gene therapy works – and it's still very much experimental – it will bring to modern medicine a revolution which will be greater than what we have witnessed since the early '50s with vaccinations. There is no comparison between the two. Surely a large number of patients initially will be cancer patients, but we have a lot of

rheumatoid diseases which are also the result of a dysfunction of a gene. You have a lot of diseases of children which are also the result of a deficit of the genes. So the gene therapy concept could be applied to a much broader population than cancer patients, even though initially there is a trial in the United States and Canada starting with cancer patients, and that's big.

2:31

THE DEPUTY CHAIRMAN: Okay. Second question?

MR. DALLA-LONGA: No further questions.

MRS. McCLELLAN: I'm not sure, Mr. Chairman, if Dan heard the earlier comment that the Cancer Board is interested in forming an endowment so that they can increase the funding and also provide some long-term stability in that funding. It's very important to them for recruiting scientists as well as the focus and the emphasis that there is on the rising incidence of cancer. So they are looking at that in the future, although what we're dealing with today is really 1994, which was the last year that the heritage savings trust fund contributed to this. We have committed $2.8 million in Alberta Health's budget for this function, which is exactly what it was in the past. So we haven't reduced any funding there.

[Mr. Dunford in the Chair]

MR. DALLA-LONGA: Just a comment. My question was spurred on by the comments that you made the last time we got together at this committee level: the alarming rate of deaths in this province. I look at some of the other programs we spend enormous amounts of money on, and I don't know what the cost benefit is on cancer research. Certainly if we spend money in this province, it benefits other jurisdictions as well, but there can't be any comparison in my mind to the money that we spend on this program and some of the other ones. I don't see the benefit like we do here.

MRS. McCLELLAN: Well, we talked about that earlier too. I mentioned in my opening comments that 10 percent of the treatments we have are considered very sound and 90 percent are considered rather experimental, so research is absolutely integral to us making sure that we do make good expenditures in those areas as well as strides.

You know, last year we did talk about breast cancer, for example. It's actually the second leading cause of death in women from cancer now. We haven't improved our outcomes or longevity an awful lot over 25 years, which is one of the reasons that we are putting a very strong emphasis on it in Alberta. As well, there have been some national initiatives in that area.

So, you know, it's a good question: what would you do? But some of the questions that have come from other members earlier today – or maybe the important question is: how do you evaluate what you're doing and ensure that those dollars have been effective? I think there's been some good dialogue on the evaluation of research, the evaluation of it once it's transferred to application as well, and that has to occur.

THE CHAIRMAN: Victor Doerksen.

MR. DOERKSEN: Thank you, Mr. Chairman. I'd like to go back, continuing on from the questions I had before, which established basically a process of reviewing research and then eventually implementing it into policy and practice. I want to turn to some specific cases, if I could. I'm not sure if you have the information, but if we don't have it, I'd request that you locate it for me.

There is some research that I've seen which provides a correlation between abortion and the risk of breast cancer. I wonder if you could tell me what conclusions you might have on that research.

MRS. McCLELLAN: Do either of my learned colleagues have the information handy?

DR. BRYANT: Yeah. There have been a few studies that have come out that have linked abortion – and by abortion in some studies they mean induced abortion, and in some studies they mean any type of abortion, either induced or spontaneous – with breast cancer risk. The very early studies were very difficult to sort out, because we also know that the fact that a woman becomes pregnant and carries that pregnancy to term, or has a live birth, early on in her reproductive years seems to be something that lowers the risk for breast cancer. Women who delay childbearing past the age of 30 or don't get pregnant at all have a somewhat higher risk of breast cancer. Sometimes it's very difficult to sort out the effect of the fact that that pregnancy terminated and didn't result in a live birth for whatever reason, that kind of risk factor, that kind of usual biological risk factor, from other things.

Later studies have been done. There are studies that are finding small effects that link the two together. There are just as many studies that find small effects that don't link the two together. I think it's something that is the subject of a review article that others are working on in the United States to try to come up with some kind of overall consensus. But the consensus right now is that if there is any effect, it's not a large one.

MR. DOERKSEN: Okay. Going to another study or research project that I think you have under way to do with prostate cancer, I believe you have a study proceeding to do with cryosurgery. Could you let us know where that's at and how that's progressing?

DR. BRYANT: There is a study under way at the Tom Baker cancer centre on cryosurgery. This is not at the point of doing a full clinical trial or what we would call a later phase clinical trial. I believe the last time I saw the data there were about 30 patients that had been enrolled in the study, and at this point the investigators are really at the phase of looking at the short-term outcomes, making sure it's not a very toxic procedure, making sure that it looks like something that it would be reasonable to run a large, randomized control trial on. They have now come close to the completion of that information and are working at developing a protocol of a randomized control trial for funding.

MR. DOERKSEN: Okay. It was my understanding that they were going to proceed, that they already had some cases lined up. I think 50 cases is what their target is.

Then the question from there is: once that's complete, how long does it take to evaluate and decide whether this has worked?

DR. BRYANT: Again, they have lined up patients; that's true. But what they haven't done is taken those patients and compared them to a group of very similar patients who got treatment in the standard therapy. Right now they're at the phase of making sure that the technology looks to be viable so that they can actually do that kind of comparative study.

How long would it take after that to know? It's very difficult to tell, because as you probably know, prostate cancer is something that can be indolent. It can be something that wasn't going to lead to death. It takes a number of years, usually, in cancer studies to be able to show a clear difference in survival between two groups. That's one of the great difficulties in doing these studies.

MRS. McCLELLAN: There's also, I wish to add, a fair amount of work going on in the U.S. in this area too, so they also monitor that work as well as they move along in this program. At the outset of developing the program, one of the difficulties was that there are so many different ways that this particular disease will act or react and maybe more so than many other types of cancers. It's going to be hard to evaluate and assess that because of that difficulty. You can't really just take two people, you know, this one and this one, and say they're going to react exactly the same in this area. But it doesn't mean we shouldn't do the work.

2:41

MR. DOERKSEN: Thank you.

THE CHAIRMAN: Okay. Thank you.

Before proceeding, we have a couple of guests again in the gallery. I'd like to welcome you. You're witnessing the hearings of the Alberta heritage savings trust fund. We have the Minister of Health, the Hon. Shirley McClellan, in front of us today. The members you see sitting on the front bench to my right are members of the loyal opposition, and behind them in the second row are the government members. We are not required to sit in our own desks during these particular hearings, nor are we required necessarily to wear jackets, but we must have ties. Women, of course, gain a little extra freedom in terms of some of the social norms that we have for males in this day and age. So welcome and thank you for joining us.

We'll proceed to Howard Sapers.

MR. SAPERS: Thanks. A couple of questions, moving away from the research and evaluation. Madam Minister, you had talked about opportunities for promotion and prevention through the regional health authorities and it was hoped that they would move more into what is now the public health division, what used to happen through the health boards. I'm wondering if there is specific direction, then, coming from your department as the regions are redrawing their business plans to begin to develop programs that may be relying on heritage savings trust fund dollars that may be forthcoming from the fund or particularly dollars that would otherwise have been spent through the Cancer Board.

MRS. McCLELLAN: Well, I can tell you the answer directly to: are they counting on heritage savings trust fund dollars to do this work? No. Are they doing some of these areas? Yes. One of the real values of regionalization is the ability to look at a needs assessment for a region, and that is something that we've not had in the past. We've had many needs assessments, you know, as many as 160 to 200, and some different groups delivering programs, whether they were in prevention or treatment. Treatment we probably had a better handle on but not much in co-ordination of promotion and prevention. It was sort of ad hoc. People knew there were some problems, and they would respond.

By having a needs assessment done, then, the regions can look at and really zero in on particular problems; for example, one that we seem to talk about often and I think should: the rising incidence of teenage girls beginning to smoke. They can look at that and develop a program and evaluate that program to see whether in fact there was some value that came out of the program, like the incidence reduced. Unfortunately, many times in the past we have had good programs, but we didn't do the follow-up.

Last year we made available an additional 7 and a half million dollars to the regions, but we didn't just distribute it. We said, "Send us your plans for initiatives on health promotion or prevention that are unique; you know, new ways to do this." We've had those moneys there in the past, so we weren't saying, "Take the money you have." We were saying, "Here's some new money." I think you will be interested when you see the type of initiatives that can and have come forward in a lot of those areas.

So we have to, I believe, put far more emphasis on this. I think there's a real opportunity for the work that is done in research, in cancer for example, and for the regions to share that information, to work together on promotion – we all read – whether it's nutritional, the work that is coming in genetics, environmental, societal. There are a number of things that we know. We've said that what we should be doing is giving the people the knowledge to make the right decisions, and we need to work on that.

I think every one of us in this room – maybe Peter is too young – probably would remember the seven danger signals. Some of us are old enough to have done cancer scrapbooks and cancer posters and the type of promotion and knowledge that was done a few years ago and is done in different ways now. It wasn't all that bad, you know, when you think that it sticks with people for virtually a lifetime. There are lots of things we can do if we maybe get back to the simple ones that work.

MR. SAPERS: There are many clinical trials – and I think this was referred to either by yourself, Madam Minister, or by Dr. Turc – that are done using experimental drug therapies on an outpatient basis, where the drugs are in fact paid for indirectly through heritage savings trust fund dollars. To the best of my knowledge that's only for cancer. Are there any other programs where drugs are provided on an outpatient basis to people who are acutely ill in this province, suffering from other illnesses and other diseases?

MRS. McCLELLAN: One of the areas, of course, where we provide funding directly to an organization is AIDS. As you know, we provide the funding to the AIDS Network, and they deliver that program for us. Some incidences can occur through a hospital program. There is no reason. Drug dollars are included in what used to be a hospitals program, now in the regions program. I've always been somewhat annoyed – is the best way to put it – when I would have a physician say to me: "You know, we're keeping this person in the hospital at a cost of $900, $1,000 a day. If you just paid for their drugs, we could reduce that cost." I thought: if you're spending a thousand dollars a day keeping them there, why don't you send the drugs, which you have in your budget and which you are giving them while they're in your institution, and let them go home at the lesser cost? To me it doesn't take a vivid imagination to work that one out. I believe that now under the regionalized system, Howard, we will see far more of that. You would know that the $110 million that we have said will be reallocated to the community programs, those dollars can be used for a community program in the best way.

One of the other areas that you and I have had a lot of conversations in is pharmaceuticals, and I think we agree in some areas in that, on effective use. I think we were all shocked when the Pharmaceutical Manufacturers Association study suggested that $7 billion to $9 billion – billion; I got it right this time – in Canada is the cost to Canada, mainly in the area of noncompliance. Everyone knows my irritation over 36 metric tonnes of drugs being disposed of at Swan Hills. We're saying that if we could reduce the waste and improve the compliance, if it's $110 million in compliance, somewhere between 90 and 110, which is the word that's been suggested in Alberta, there would be a lot more money for use of drugs effectively, whether they be cancer drugs or drugs for AIDS or drugs for other chronic ailments. There are a number of chronic ailments that people depend on drugs for. So, yeah, it's an area we need to really, really look at. With reduced stays in acute care this

becomes more of a problem for people who don't have drug programs or insurance programs.

2:51

MR. SAPERS: Perhaps my last question for the day. Dr. Turc, will it be your practice to deal with requests for information relating to Alberta Cancer Board operations and Alberta Cancer Board funded initiatives as though they were fully subject to the freedom of information and privacy legislation that is currently in place in the province?

DR. TURC: I believe that we are indeed subject, but there is a window. I can't remember if we will start to be subject to that in two years from now or three years from now.

MRS. McCLELLAN: Three.

DR. TURC: Yes, indeed we are part of it.

MRS. McCLELLAN: They are part of it, but there is also, as you know, some protection for confidentiality of information for people's personal medical information.

MR. SAPERS: During the transition period?

MRS. McCLELLAN: Yes, there is, and I believe it's three years, if I remember correctly. I can't remember whether that's when it started, when it first came out, or whether it started from October but somewhere in that range.

THE CHAIRMAN: Okay. Thank you.

MR. LANGEVIN: Mr. Chairman, I'll pass on my question, and I'll move that we call it 3 o'clock.

THE CHAIRMAN: It's not 3 o'clock.

MR. LANGEVIN: No. I have one quick question in the context of cancer research. I know that one of the main drives is towards a cure and prevention of the actual disease, but how much money do we spend on lifestyle, which would not include cigarette or alcohol abuse but the actual food that we eat, diet, the value of certain foods towards cancer prevention or cancer cure, and the value of certain food additives, whether there's any value towards cancer prevention.

MRS. McCLELLAN: So you're wondering how much money is spent on research in those areas?

MR. LANGEVIN: On the food side of it.

MRS. McCLELLAN: Do we have that type of information, Judy?

MRS. BARLOW: Not off the top of my head.

DR. BRYANT: I don't have actual numbers. I can tell you that there is a study right now that is under way looking at physical activity, diet, and breast cancer risk. Physical activity is one of the lifestyle issues that's being related to that, and because physical activity and diet are very closely linked, information will be collected on diet as well. That particular project was approved by the ACB research initiative program, but because it also received funding nationally, the national funding was used for that project.

MRS. McCLELLAN: We might be able to have a look at what information we'd have available for the last year on research projects in Canada and give you some idea, through you, Mr. Chairman, as to the dollars that were expended in that area. It would be quite interesting to know.

MR. LANGEVIN: That's it. Thank you.

THE CHAIRMAN: Debby.

MS CARLSON: Thank you. In the past dollars from the heritage savings trust fund have been used to purchase equipment within health facilities. The RHAs are currently running a $100 million deficit due to depreciation. Are there any current plans or will an application be made sometime in the future to transfer funds out of this fund and into the RHAs?

MRS. McCLELLAN: Well, I should clarify something. I think we're stretching the point to think this has very much to do with the cancer research fund, although the lottery dollars funding, which is about $8 million a year, did contribute to the new linear accelerator and, I believe, purchased the MRI that's at the Cross.

There is one thing I want to correct. Capital has not been taken from the regions. It's interesting when you do this. As you know, in many budgets we have dedicated line items. You will give a specific amount for capital. You will give a specific amount for home care. You give a specific amount for acute care, et cetera. One of the things that we always hear and I know that municipalities said the same thing: instead of giving us conditional dollars, give us the envelope, and then we'll look after things. Well, the capital dollars are included in the envelope, and while, yes, all regions have faced reductions over the last two years, we did not take away capital funding. We no longer put it as a line item. Regions were told very clearly that this was going to occur and that they should manage their capital, as they had to do in the past when it was a dedicated item. So they are looking at that.

There still are lottery dollars for capital equipment, but that is generally for large pieces of equipment that are very expensive, new things that come along like the MRIs, the blaster of stones – I've never mastered the name of that critter yet – and so on. So, yes, we still have that component. We have not taken away the capital dollars from the regional health authorities. Capital was included in their overall global budgets. Really the only area that we've been very specific in saying you couldn't reduce was home care. If you remember the reductions we had last year, we said that there were two areas where they could not find that money: one was home care, and one was speech pathology.

As much as possible, Debby, we are trying to give the regional health authorities the opportunity to manage the money. What we want to make sure is that they are funded appropriately so that they can carry out that management. As you know, we are looking at a funding formula that could be different than the one we have, which would allow more transparency and better understanding of how funding does occur.

MS CARLSON: Just one more follow-up to that. That's good – and thank you for that answer – but they are facing a paper deficit at this point anyways. Would there be any transfer of funds from here to there to cover that deficit?

MRS. McCLELLAN: Well, if you're asking directly if we are going to transfer research dollars to the regional health authority to look after an operating deficit, the answer is no.

MS CARLSON: Anywhere within the heritage savings and trust fund dollars?

MRS. McCLELLAN: Well, we don't have any other dollars in the heritage savings trust fund in Health. We don't have any anymore. You are talking about last year. Those dollars are spent, with the exception of what was carried over. We are dedicating in our budget $2.8 million for cancer research. I think the history of us maintaining it has been there, and I welcome you challenging the minister if you see a reduction in those areas.

MS CARLSON: Okay. Thank you.

THE CHAIRMAN: Are you finished?

MS CARLSON: Yeah, I think so.

THE CHAIRMAN: Any other questions from any member? Does any member wish to read a recommendation into the record at this point?

MRS. McCLELLAN: Can I . . .

THE CHAIRMAN: Go ahead.

MRS. McCLELLAN: I think I made my comments at the outset on thanking the committee members. Maybe all weren't here. I think that all of the times that I've appeared before your committee, Mr. Chairman, there have been very positive, very productive, very good questions. I believe that Dr. Turc and Dr. Bryant would say the same thing. We want to say that we appreciate the support that we have received from members on both sides of the House for cancer research and thank you for your involvement when you were funding it through the trust fund.

THE CHAIRMAN: Okay. Thanks, Madam Minister.

It being the hour of 3:01, I'll declare the meeting adjourned.

[The committee adjourned at 3:01 p.m.]