

Transcript

Event: **NATIONAL PRESS CLUB** Date: **06/06/2001**

Slip ID: **C00004160331** Time: **1300**

Item: **'THE REVOLUTION IN HEALTH RESEARCH: THE TWENTY-FIRST CENTURY VENTURE'**

SPEAKER: DR ALAN BERNSTEIN (PRESIDENT, CANADIAN INSTITUTE OF HEALTH RESEARCH)

PRESENTATION OF THE RESEARCH MEDAL ON BEHALF OF THE AUSTRALIAN SOCIETY FOR MEDICAL RESEARCH BY DR MICHAEL WOOLDRIDGE, THE MINISTER FOR HEALTH AND AGED CARE

COMPERE: Ladies and gentlemen, welcome to today's National Press Club Telstra address.

We're very pleased to welcome Dr Alan Bernstein here today. It's almost a happy birthday occasion for him. He is the inaugural president of the Canadian Institute of Health Research which was established, according to our calendar but not quite according to Canadian time, exactly one year ago.

It's a quite different approach to medical research from the one that existed before. And he will tell you more about that, and also about the new era in medical research that we're in at the moment.

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ABs = Managers, administrators, professions. GBs = Grocery buyers.

But quite apart from that, Dr Bernstein is this year's recipient of the medal of the Australian Society for Medical Research. And to begin today's proceedings I would like you to welcome the Minister for Health, Dr Michael Wooldridge, who will present that award to him. [Applause]

MICHAEL WOOLDRIDGE: Thank you Ken.

Distinguished guests, ladies and gentlemen:

I am delighted to welcome Professor Bernstein to Australia and have the privilege of presenting him with the research medal on behalf of the Australian Society for Medical Research.

It's important to point out that in the same spirit as a Melbourne radio station that only plays songs less than 12 months old, the ASMR enforces their relevance by passing over anyone for the board of Directors who has reached the age of 45.

Alan and I aren't quite so lucky in our jobs, I'm afraid. In fact Alan is in the midst of a remarkable career in health and medical research that began with a PhD in medical biophysics from the University of Toronto in 1972, included further studies at the Imperial Cancer Research Fund laboratories in London, and was followed by a period at the Ontario Cancer Institute.



Subsequent appointments included professor of molecular and medical genetics at the University of Toronto, and head of the molecular and development at the Samuel Lunenfeld Research Institute at the Mount Sinai Hospital. All this before becoming director of the Institute in 1994.

Alan made critical advances in our knowledge of embryonic development, cancer, haematopoiesis and the formation of the cardiovascular system. As well he has contributed strongly to gene therapy techniques and the genetic analysis of mammalian development.

He's also noted for his empathy with students and contributions to outreach programs in schools and the wider community.

His scientific leadership activities have been recognised through numerous previous awards and honours. He is the author of nearly 200 refereed articles, as well as being a highly valued consultant internationally.

Finally, he was a member of the National Taskforce on Health Research that recommended the establishment of the Canadian Institutes of Health Research of which he is now president.

These 13 virtual institutes provide an exciting model for research management, with each focussing on a



different discipline within biomedical science, clinical science, health systems and service, and examining the social, cultural and other factors that effect the health of populations.

Alan's leadership role and understanding of the issues underpinning modern health and medical research give him a valuable perspective that makes him an extremely worthy recipient of the medal.

His visit has particular relevance for Australia, given the similarities between Canada and Australia in terms of our society, government structures, and our aspirations for health of our respective communities.

As we'd know, medical research is increasingly an international endeavour, and Australia faces a considerable challenge in matching our reputation for great science, from Florey to Doherty and beyond, with administrative, educational and commercial structures and cultures that will ensure Australia is competitive within the international medical research marketplace.

Alan is uniquely placed to bring a fresh and valuable perspective on these vital issues.

On everyone's behalf I thank the Australian Society for Medical Research for instituting this award and choosing such a worthy recipient in Professor

Bernstein, to whom I am delighted to present the Medical Research Medal.

Thank you. [Applause]

ALAN BERNSTEIN: Minister, thank you very much.

And Mr Randall, colleagues, ladies and gentlemen:

It's a real delight and surprise, given the fog in Sydney this morning, for me to be here. And of course it's a great honour for me to be named this year's ASMR medallist, particularly given the previous winners of that award ? Peter Doherty, Bridget Ogilvey, to name but two great Australians.

I'm also, of course, very pleased to be in Australia. Australia is one of my favourite places to visit. On my last trip here about five years ago my wife Joanne said to me (it was here first time and my second) that if I ever wanted to move, Australia would be the only country that she would agree to move to.

I'm not fishing for a job, but just ? ! [Laughter]

And of course with the Australian Society for Medical Research, I share their passion for raising the awareness about the importance of medical

research. And so I'm very pleased to be part of this week's national activities here in Australia.

While the distances between Canada and Australia are immense, Canadians have a great affinity for Australia. We have so many things in common. We share a common European heritage ? a heritage that is augmented and strengthened by immigrants from many cultures that have come to our two countries over the last hundred years. We both, of course, have also large indigenous populations, whose place in our societies have not always been honoured, but who have a great deal ? from whom we have a great deal to learn and to provide back.

We are both, of course, huge countries with a widely dispersed population, and yet despite many myths about our wilderness, we are both of course probably the most urbanised countries in the world. We are both influenced by our neighbours. In our case our obvious neighbour is the United States. In your case the entire Far East. Both of our economies have been traditionally built on natural resources and manufacturing. And both countries, of course, have government run health care systems. So we also share the challenges posed by national health care systems that need to meet ever changing and ever complex demands.

I'm sure that the most ? that our health care system will be vastly different in 10 years than it is today.



I'm also positive that research will be the major driver of that change over the next 10 years.

And the reason I think is obvious. We are in the midst of a very profound revolution in health research. It's a revolution that is being driven by a rapidly emerging understanding of the molecular basis of life, of human biology and of human disease. We're at the early stages I think of this revolution. And it's truly a ground-breaking revolution in health research. It started with genetics and moved on quickly to genomics, has spread to proteomics, functional genomics. These are words that really the public is familiar with because you read them everyday in the newspapers. And we'll very shortly I think embrace a coherent and therefore much more satisfying examination of all the determinants of health ? our environment, lifestyle, psycho-social, economic determinants of health and their interplay with our genetic heritage.

I think this is truly the century of health research. It's the bio-century.

Our ability to identify people with genes that make them susceptible to a given disease is also going to mean a profound shift in health care from disease treatment to disease prevention and health promotion.



As we understand the intricate and intimate molecular mechanisms that underlie disease, we will be able to develop an entirely new approach to discovering drugs designed to interfere with the molecular machinery that's altered in disease.

The development of totipotent stem cells ? a point that's been in the newspapers literally every day in the last five days since I've been here in Australia ? that have the ability to give rise to many different cell types, and therefore to replace potentially diseased or dying cells, offers the potential to cure diseases as diverse as diabetes, spinal cord injuries, cancer, Alzheimer's, Parkinson's disease, and it's opening up entirely again new therapeutic possibilities.

These scientific advances are not so simple though. As you know, they raise complex ethical, legal and social issues that we as a society and as a scientific community cannot ignore.

Knowing that you're susceptible to a particular disease decades in advance can effect decisions about all aspects of your life. Others having that knowledge have implications for areas such as employment and insurability.

The use of stem cells derived from human embryos is raising obvious issues for society, and that's been again discussed at great depth here in Australia and also in Canada.



And so we need a way of discussing this rapidly advancing new science that brings our public along with us. This can't be decided by scientists. It has to be decided by citizens.

These new drugs will be effective, they'll have fewer side effects, but they also will be expensive. That will raise new challenges for governments in both our two countries in this new era of health research.

The leaders in health research will be those countries that are nimble and that take an integrated and intra-disciplinary approach in order to consider these issues and to ensure that the changes in our health-care system are evidence based and truly respond to the needs and priorities of our two citizens.

A stronger health-care system is only one of the outcomes of a strong and innovative health research enterprise. A healthy and growing economy is the other.

I think we're already experiencing this in Canada, and I think you are also starting to experience this in Australia.

The health-care system is our largest knowledge based sector. In Canada it probably represents about 14 per cent of the Canadian economy. Health research contributes significantly to jobs and growth in Canada's economy. In fact today the life



sciences in Canada account for about 86,000 jobs, and it's been forecast that that will grow to about 130,000 by 2003 ? two years from now.

Already there are more than a hundred publicly traded bio-technology companies in Canada, with a market value, even after the collapse, of close to \$15 billion ? Canadian dollars.

Success in this sector depends critically, absolutely, on research and innovation. Academic research is *the* well-spring that drives the growth and success of the biotechnology sector.

A study conducted for the National Science Foundation in the United States found that almost three-quarters (72 per cent, to be exact) of patents on commercial products in the biotech sector could be traced directly back to government funded university research.

In Canada, government funding has led to many commercial spin-offs, including most recently one that I was pleased to be part of an announcement of just last week ? of a company called Blueprint Worldwide. And I think it represents this new world we're in ? a partnership between the Canadian Institutes of Health Research, researchers, a venture capital fund represented by a company called MDS Protionics in Canada, and IBM Life Sciences.



And Blueprint's business plan is to catalogue all of the protein, protein interactions in a living human cell and to make that available to companies that are into drug design, because that information is vital to this new generation of a new way of developing new drugs.

So the link between investment and health research and a strong and growing economy I think is clear. And that's I think one of the main reasons that the government of Canada has committed itself to investing in research and development.

In fact it has set as its goal for Canada to become one of the top five countries in the world for R and D performance by the year 2010, and we actually are ? our two countries are actually neck and neck at being around fifteenth at the moment. So that's a significant challenge certainly for Canada.

As its contribution, the government ? our government ? has pledged to double its current investment in R and D over that time period.

So the Canadian Institutes of Health Research is a key part of that investment. With its creation, as Ken said, exactly one year ago, and the absorption of the now defunct Medical Research Council of Canada (which CIHR replaces) the government of Canada has doubled in two years the amount it invests in health research ? from about \$235 million



to about \$470 million on an annual basis. And in this year's speech from the throne in January, the government pledged to further significant increase in the budget for CIHR.

But CIHR is more than just about more dollars. In Canada the local expression is 'CIHR is not MRC on steroids'. CIHR is a very different organisation. Our mandate, as the minister said, includes not just biomedical and clinical, but also includes health services, health systems research and population health research, and the interplay between those four pillars of research that impact on health.

In addition, CIHR, or the act that created CIHR envisioned the creation of institutes ? virtual institutes ? that would bring together researchers, health charities, industry, all levels of government, international partners, to focus on particular areas of concern in health research.

So we have created 13 institutes. They range from, sort of, traditional ones such as cancer, circulatory and respiratory health to perhaps more novel ones such as gender and health, Aboriginal peoples health, population health, and health services research.

We fund across Canada approximately 5,000 investigators and train roughly four to six thousand

young people who have chosen to make a career in health research.

CIHR is only I think one part of the picture of the government of Canada's commitment to R and D. In addition to creating CIHR, the government of Canada has also created the Canada Foundation for Innovation. It's a \$3 billion initiative to upgrade and modernise the research infrastructure of our universities, hospitals and research institutes across Canada, and also to provide start-up funds for new investigators who are choosing to come to Canada.

The Canada Research chairs is investing almost a billion Canadian dollars ? 900 million ? in creating 2,000 chairs, about a third of which is in the health area, for research across the country, both for internationally renowned, established researchers, and also for beginning, young, new researchers.

Genome Canada is a \$300 million investment to establish genome platforms in about six centres across Canada to make sure that Canada is a full participant in the generation of knowledge arising from our growing understanding of the human genome.

One of my priorities as president of CIHR is to nurture international partnerships. Australia and Canada have a great deal to offer one each other in my judgement. We share, for example, excellence in



many areas of science, including cancer research, a shared focus on Aboriginal health issues that encompass genetics, environment, and the lifestyle determinants of health.

Just recently I had two postdoctoral fellows in my own laboratory from Australia working with me. I would add quickly that they've returned to Australia. And I'm looking forward to seeing them tomorrow in Melbourne.

Science is international, and both our small countries need to enrich our perspectives by this sort of exchange of people and of shared goals and objectives and dreams.

So in conclusion, I believe passionately that a sustained and significant investment in health research is a reflection of the very best in our two countries. It acknowledges that an innovative, creative, cost-effective and sustainable health-care system, capable of providing the very best health delivery during this profound period of change driven by the health research revolution, can only be ? must be underpinned by a vibrant, proactive, integrative and internationally competitive health research enterprise. It reflects the importance we give to the health of our two populations. It provides opportunity for young people. It acknowledges our role as First World countries in addressing the various serious health challenges of

all of humanity. It diversifies and strengthens our economies away from the traditional resource and manufacturing sectors to the new knowledge-based economies of the twenty-first century. And it acknowledges in this new century, I think, that success for our countries will be measured by the health of our citizens, by the extent to which the energy, creativity, intellectual power of our young people can be channelled into creating a culture of discovery, a culture of innovation, and a culture of excellence.

So, thank you so much for your attention and for this great honour. I appreciate being here very, very much.

Thank you. [Applause]

CHAIRMAN: Thank you very much Dr Bernstein, and congratulations.

ALAN BERNSTEIN: Thank you.

CHAIRMAN: As usual we have a period of questions, and the first one today from our media members is from Elizabeth Gosse.

ELIZABETH GOSSE: Dr Bernstein, Elizabeth Gosse from AAP.

Do you think that Australia is showing signs of being nimble enough to succeed in this research revolution?

ALAN BERNSTEIN: I've been very impressed the last three days that I've been here with the quality of the researchers I've been meeting with. I was in Queensland on my first day in Brisbane. I visited the QIMR and seeing the beautiful new buildings that are going up there, enthusiasm for the IMB (the Institute for Molecular Biosciences) that's being built there. So I would say you are building on strength, and I would encourage you to keep doing that. I think you have a history of excellence in research that ? going back to Florey, Barry Marshall, Peter Doherty. It's just outstanding for a country with a small population.

CHAIRMAN: Mark Metherall.

MARK METHERALL: Mark Metherall from the *Sydney Morning Herald*, professor.

You mentioned the problem of the ethical questions flowing from these advances in cloning and stem cell research and the like. How had Canada approached the public debate on this?

The Prime Minister here two weeks ago announced that the Council of Governments, which includes state and federal governments, will this Friday

discuss a uniform approach. We have ? the states have a role in the law making in this area. But it always strikes one that the public debate is always lagging the technical advance. And this has become particularly true of bioethics. How had Canada done it? And do you think two weeks notice of a leader's decision on uniform approach is enough for the public?

ALAN BERNSTEIN: What's happening in Canada is several-fold.

First, the CIHR tabled a working group of researchers and ethicists to come up with guidelines for CIHR funded research. That report was ? a draft of that report was tabled. It's on our web site. And it's open for discussion until later this month actually. This was a sort of a three-month discussion. And I'm happy to go into the, sort of, the nuts and bolts of the recommendations.

But ? and secondarily, the Minister of Health, Alan Rock, has tabled draft legislation in the House of Commons on assisted human reproduction, which includes issues around stem cells and human cloning. And that's draft legislation that will be discussed in parliament and in various committees in parliament over the next few months before it goes, sort of, to file form of legislation.

So, these are complex issues, very diverse views. The position that Canada has taken is, at the

moment is, first, there will be one set of rules for the country as a whole. Secondly, that human cloning will not be allowed. And thirdly, that the use of embryos that are developed by in-vitro means for assisted human reproduction, up to I think about day 14, can be used to generate new human embryonic stem cell lines. But these lines cannot be generated solely for research purposes. And there's a number of other details that we could go into.

CHAIRMAN:

Do you want to go further? I mean, it has been fairly extensively canvassed here ? some of those issues.

ALAN BERNSTEIN:

Well, I'm happy to talk about it. I think this illustrates, if you will, I think the challenge facing our societies ? how do we balance, I think, valid points of view, both from the patient perspective ? sort of, the Christopher Reeves of this world who elect to have a cure for spinal cord injuries, the diseases I mentioned in my talk, and people who feel that human embryos are not just a collection of cells, but they are little humans; and lots of people who feel ? are worried about the ultimate commodification of life ? 'Are we going to generate human embryos and have them for sale?'

So, these are important challenges that need broad discussion.

MARK METHERALL: Can I just ask then ? the 14-day limit you mentioned on the embryos. Could you just go through that in more detail?

ALAN BERNSTEIN: I think that the thinking there was, this is 14 days ? a large number of people would view this as being, these are now just cells, there is no obvious aggregate structures in a human embryo at that stage, certainly during normal reproduction they are not yet at the implantation stage. And from a scientific perspective, they are most likely to retain their totipotency in being able to give rise to very many different cells types for therapeutic purposes.

CHAIRMAN: The other thing that's implicit in Mark's question is the that we've arrived at a situation in this country where there are different legal regimes governing research and medical practice in some of these areas. And that's one of the things that's prompted the Prime Minister's approach to this.

What is the situation in Canada now as opposed to what you're trying to reach?

ALAN BERNSTEIN: At the moment there are no guidelines in place whatsoever. I think the provinces (which is our equivalent of your states) is looking to the Federal Government to develop a single set of national guidelines for Canada.

CHAIRMAN: Thank you.

The next question is from Leah de Forest.

LEAH DE FOREST: Hi.

I was just wondering, with the research at a molecular level, do you think for instance we'll one day be able to completely control the immune system?

ALAN BERNSTEIN: It's always dangerous to predict the future.

I think I can safely predict that one day we will completely understand the immune system and be able to exploit that information to deal with diseases ? you know, auto-immune disease, to the extent that the immune system is important to cancer. Whether we'll be able to control it ? that's the great unknown. And that's true for every system in our body. And that's what makes research so exciting.

There's no question that we are moving to a period of understanding of this complex machine that is our body ? no question about that.

CHAIRMAN: The next question is from John Kerrin.

JOHN KERRIN: Dr Bernstein , John Kerrin from the *Australian*.



I wonder if I might expand on that a little. You mentioned in your speech that over the next 10 years health care is going to be revolutionised. I'm just wondering if you could briefly lay out a picture of what a visit to the doctor might be like or what might happen to you in a hospital? I mean, can you sort of see what is going to happen on that front?

ALAN BERNSTEIN:

Let me start with I think what's already starting to happen a little bit, just to set the stage, and then extrapolate from there.

So at the moment we have identified (*we* being the research community as a whole) some of the genes that are involved in even complex diseases like colon cancer and breast cancer. So about 10 per cent of each of those disease is due to inherited mutations in known genes. So we have the ability to sequence those genes and determine decades in advance who's going to get colon cancer or breast cancer if they have a family history and therefore there's a reason to be sequencing it.

And so if you have a family history of colon cancer, you can have your FAP gene sequenced. And if you have a mutation, you have about a 95 per cent chance of getting colon cancer.

The good news is, because of that, you can be followed very closely by endoscopy and colonoscopies, and have these pre-malignant polyps



removed before you get colon cancer, and prevent what is otherwise inevitably a lethal disease.

Breast cancer provides the kind of the contrasting challenge. Again, it's easy to sequence the BRCA1 gene or BRCA2 gene and identify those women who are going to get breast or ovarian cancer due to a family history or mutation in those genes. But there's not much we can do about that, having got that information.

I guess I'm an optimist. I think that being able to identify people who are at risk of getting disease will prompt a whole new kind of research develop ? prevention strategies and prevention drugs.

So, to go back to your question. X years from now (and I won't be pinned down to what x is) I can imagine a day where you will come in to the doctor and he'll take a swab of saliva or blood to extract your DNA. It'll be then analysed by gene chip ? gene wafer technology ? to look at all the genes that we know 10 years or x years from now that predispose to all the kinds of diseases that we're susceptible to. And then say to you, 'Look, you know, you have a very high probability of getting melanoma because you're not very good at repairing the damage caused by ultra-violet light and sunlight. You really should take precautions.' Or 'you don't', etc., etc. 'You have a high propensity



towards diabetes, and therefore I would advise you to keep your weight down and exercise a lot.'

mean, there's lots of scenarios one can play out. I can imagine drugs being developed that will be designed to prevent those diseases, because we can identify people who are at risk.

I also can imagine that once you have a disease, instead of just saying 'you have schizophrenia' we will do DNA tests to actually understand what the molecular basis is of that particular form of schizophrenia that you happen to have, and the treatment will be individualised based on knowing the underlying molecular basis of that disease. And so I think we are moving into really an important and exciting new era.

Just to end up here. The analogy I like to give is: if your car doesn't work, it matters to know why. It's important to understand what's wrong with your car, because otherwise you can't fix it. If it's true for our cars, it's at least as true for our own body. And despite what most people think, we really don't understand most common, serious disease that afflict humanity.

CHAIRMAN:

Doctor, just extrapolating from that, going back to something you mentioned in passing in your address: when it's possible to become as specific as that at the doctor's surgery, how do you think the

issues such as insurance, for example, that you mentioned before, should be addressed?

ALAN BERNSTEIN: Well, the short answer is: it's not for me to say. I think it's for society to say.

Yeah, as I mentioned in my talk, insurability, employability, if we can predict who's going to get disease, is a big, new issue.

Two realities though. All of us are going to die. That's number one. We will die of something. That's number one.

Number two: we all are going to be ? we all carry mutations in genes. That's a given as well. And so in the end there may not be ? it all may be an equaliser. There may be no advantage or disadvantage if people share information.

And third: we can decide, as a society, that that information is our privileged health information and not to be shared with anyone else. We do that with other health information. This is, in a sense, no different. And that would be the one that I would advocate.

CHAIRMAN: Thank you.

The next question is from Sue Dunlevy.

SUE DUNLEVY:

Sue Dunlevy, *Daily Telegraph*, Dr Bernstein.

Of course the issues go much beyond that. You talked about the example of your car breaking down and you'd want to know why. But in this case you would know before you bought the car what was going to happen to it in the end, and why would you outlay the money.

So, how are people going to cope with the problem of knowing that 10 years down the track they might die of cancer of some kind or possibly develop multiple sclerosis or some other life threatening and life depleting disease?

And secondly: is there much point in discovering that we're going to develop these diseases and knowing that we're going to develop them unless we also know that we can do something about it; or that if we can do something about it, it might be too expensive for us to afford to prevent it or treat it?

There's an example of a drug that's being discussed by our Drug Subsidy Committee this month which costs \$18,000 a year to deliver. If every arthritis sufferer in this country got that drug, it would cost the same amount as our entire drug subsidy scheme does at the moment. So, can we afford some of the breakthroughs that medical science is making?

ALAN BERNSTEIN: Well, just on that last point. You were echoing what I said in my talk ? that these new drugs are going to be effective, but they're also going to be expensive, and that's going to create challenges for our health-care systems.

To go back to your first point. Yeah, I think you've raised interesting and very relevant and important points.

It's interesting that when studies have been done (and they have been done) of women who have a family history of breast cancer or if there's a family history of Huntington's disease, for example (and these were ? one study, the first one was in the United States and the second one was one that was done in Canada) these are diseases that clearly run in families. Huntington's is a very terrible, neuro-degenerative disorder. It strikes late in life.

It's interesting. Most people, first of all, assume that they are carriers of the mutation. So they assume the worst. And so the genetic testing can only bring good news. That's number one.

Number two: the United States' study, when they asked women 'would you like to be tested for mutations in your breast cancer one or breast cancer two genes, knowing that there's nothing we can do about it', overwhelmingly people in that country ? the women in that country said 'yes we would like



to know ? we would like to know so we can make informed decisions about careers, marriage, children, etc.’ And so when asked, people have said ‘we would like to have that information’.

As I said, I’m an optimist. I think knowing is always better than not knowing. The one thing we do know is we’re going to die of something. And if we know what we’re going to die of, it is going to be a different world.

It’s well ? also I should stress this, that I’m talking now at the moment of diseases which effect, let’s say, 10 per cent of those women who get breast cancer. So, these are not the majority.

We are though potentially getting to what we call in research the complex diseases like diabetes, mental illness, that are a complex interplay between environment, lifestyle, psycho-social issues, and maybe more than one gene, so that it’s not so clear, if you have a form of a gene that might predispose you to getting schizophrenia or diabetes, that you will actually get it; that there may be other non-genetic factors that can ameliorate the disease or the severity of the disease.

And now I’m projecting because I don’t know this for a fact. So there is going to be some potential to actually do something about it ? to actually change your lifestyle if you know that you’re prone to

diabetes ? you shouldn't have a lot of sugar; you should make sure that you really exercise and keep your weight down.

So I think there are a lot of good news within this as well as some new challenges which ? you're absolutely right.

CHAIRMAN:

Doctor, just before I invite the next question, could I go back to your address again and the figures you mentioned ? the funding figures ? it's a rather startling prospect that government in this day and age and era or economic rationalism can agree to double this sort of funding.

How did that come about? There must have been some sort of change in ? or some sort of cultivation of public opinion to make it possible?

ALAN BERNSTEIN:

An interesting question.

In Canada there was ? I think it's fair to say that research was never viewed, certainly as a member of the research community, as being important to government. It was always a frustration certainly that I had. And in the nineties when the old Medical Research Council's budget was being cut 3 to 4 per cent a year for, sort of, five years running because of federal deficits, sort of caught up in the general cut-backs, I think the research community finally woke up and said 'we need to send a signal to



government that we are in danger of losing Canada's research community if this continues'.

And I guess I would say that message got through. And many people ? many variable played a role in that. But I also think it's fair to say that the government of Canada is now ? really understands the importance of research to the future of Canada and the importance of making sustained investments in research. These are not, you know, one-time, pre-election. These are long-term issues. You can't turn the research tap on and off. That's the quickest way to kill it in fact. People will just flee the country if they think there isn't a firm belief in what's going on.

As I said in my talk, we are very close to the United States. The National Institutes of Health budget in the US has doubled and doubled again. So it's now in the \$24 billion range. In President Bush's latest budget, every activity of government was cut except one, and that was the NIH budget, which went up by I think 14 per cent, or maybe it was 18 per cent.

And given that reality, I think all of us have to ask 'What's our future economy? Where is the Canadian economy going? Where is the Australian economy going?'

It's cheaper to make clothes and cars, etc. in Second and Third World countries. Labour is



cheaper. That's a reality. That's a fact. So, where is the future for countries like ours?

It's got to be in the new economy. It's got to be in creating new knowledge, and exploiting that new knowledge in creating jobs. And there's two areas: biotech and high-tech, at the moment. And I have no doubt that in the long run biotech is by far the most important, because what's more important than our health!

You know, I lost myself on somewhere this morning. I will live without it. But I won't live without my health, by definition. And so one doesn't have to create a market for good health.

CHAIRMAN:

Can you tell the research community here how your research community got that message through?

ALAN BERNSTEIN:

I think it was out of desperation initially. I think there was ? it always pays to speak in one voice and to give reinforcing messages. And so that's why I think organisations like the Australian Society for Medical Research is so important, because it really is a coalescence of researchers who are now speaking with one voice. I think it's also very important to have people who are outside the research community ? the health charities is a good example; industry is a very good example ? who reinforce those message, that this is not just a self-serving message coming from the research

community. And so it was that coalition in Canada coming together that really I think made government sit up and listen, and in the end develop their own agenda of why research is so important to the future of Canada.

CHAIRMAN: Next question.

MICHELLE SINGER: Michelle Singer from the *Financial Review*.

In your address you said that the funding in your country was for all sorts of medical research. So I was just wondering whether Canada had toyed with the idea of health information technology, and whether ? well, what your thoughts were on this sort of subject? Because I know in Australia we're considering this sort of system where patients' health records go online. And I was just wondering if you thought that this sort of system would have a chance of being manipulated, or that this sort of steps over the line of patient confidentiality?

ALAN BERNSTEIN: The short answer is yes, Canada is thinking very seriously about, and is doing actually ? going into, sort of, this new world of health information technology. And I agree with you, there are issues of confidentiality and privacy that's raised by sort of web based transfer of information.

But the alternative, you know: to me it's crazy if you go into an emergency room for whatever reason

? a heart attack, a car accident ? your health status and all the records that the physicians need to see as quickly as possible have to be transferred by hand from some other place, and it takes days, when we have the technology to send it within seconds.

And so what we need then is to make sure that that information, even if it goes across the web, is private, and there is technology to keep it private. So we have to ensure that happens. But I think it's doable.

And again, I think in countries like Canada and Australia where the distances can be vast, and many, many people in our two countries live in remote communities that don't have immediate access to teaching hospitals and tertiary health-care centres, we need ways of transmitting that information back and forth quickly to make sure that people in remote communities get the very best health care.

Should health information technology be compulsory?

MICHELLE SINGER: [Inaudible] ...

ALAN BERNSTEIN: I haven't thought about it, is the honest answer.

I think it certainly would make it simple to have a uniform system for everybody. I guess you could

have an opt-out provision in that. But it's probably one ? only one of many, many issues that will come up in developing this new technology.

CHAIRMAN: Mark Metherall.

MARK METHERALL: Professor, you spoke just before about the increasing cost of the drugs that are going to flow from the new biotechnology.

We already see the amalgamation of most of the big international pharmaceutical conglomerates into even bigger and fewer groups. Given the rising influence in cost of the drug companies and their products, is there a significant issue here for the future direction of medical research? To what extent does the pharmaceutical industry influence and even control it? And what is a country like Canada doing about that?

ALAN BERNSTEIN: That's an important question. I think it's important both for the long-term future of the pharmaceutical industry and the independence, if you will, of academic research that the pharmaceutical industry be a partner but not be the major driver. And I say to their advantage, because long-term discovery and innovation really requires a patient investor, whether that investor is government or whether it's industry. And so the unique thing that academia can offer to industry is exactly that ? the long-term view and the fundamental research.



And so I think it would be short-sighted for industry (and I know that they are aware of this) to push the agenda in academia so that it's really just a clone of what's going on in their own pharmaceutical houses. It doesn't make sense. It isn't good business.

So my own view on partnerships with industry is they have to be entered into understanding that both partners have in the end some common objectives and some different objectives. And those have to be acknowledged, respected, etc.

But I think not to enter into those partnerships would be a mistake as well. We need industry, not actually just for their money ? although money is nice ? but we need industry for all kinds of other things as well ? access to new technologies, access to patient trials, access to information. And they clearly need the academic research going on at universities and hospitals and the minds that are there. And so there's a congruence there that could be ? is being used to mutual advantage. And there are many, many, many partnerships in this country (I've heard about them in the last few days) and I certainly know in Canada, that work wonderfully, that serve both parties well, that accomplish those goals to mutual advantage. And so they can be done well if everyone acknowledges the challenges.



But, you're absolutely right ? the driver has got to be the desire to acquire new knowledge, and then to apply it to human health.

CHAIRMAN:

Alan, just going a bit beyond that. Michael Wooldridge ? who's had to leave us to go back to parliament ? only yesterday was talking about the growth and expenditure on our own pharmaceutical benefit scheme (that's the subsidies for drugs). And the most recent figure I think was a 13 per cent increase, which he thought was quite good, given the past. But it's still a vast amount of money.

Will the new technologies at some foreseeable point start to reduce the cost of drugs; or are we looking at those sort of costs as far as we can see?

ALAN BERNSTEIN:

Yeah. I think that the new drugs that come through the pipeline are going to be expensive, as I said. And so we need a macro look at the total cost to the health-care system. So, if a drug which costs \$100,000 for a course of treatment for a patient, let's say, with cancer, actually works, as opposed to a \$10,000 drug that may prolong life a little bit and it's very toxic and requires extensive hospitalisation afterwards because of the toxic side effects, what we have to do then is look at the whole system and balance the cost of the drug against the cost to the health-care system because of the side-effects, hospitalisation. And in the end, many of these drugs are not particularly effective.

But there's no question the cost of drugs is going to go up ? is going up.

I'm not here as an apologist for the pharmaceutical industry, obviously. But I think that is a reality.

I think the other thing to keep in mind is in the long-term these new drugs have to be afforded. Nobody can make a product that nobody can afford to buy.

And we had a good example of that with the pharmaceutical industry and the huge tragedy of HIV-AIDS in Africa where there are drugs that can not quite cure AIDS, but certainly can dampen it and extend life quite significantly. But nobody in Africa could afford those drugs.

The pharmaceutical industry ? under some pressure ? but the pharmaceutical industry has lowered quite significantly the price of those drugs to make them available to consumers in Africa.

I think the general principle is the law of supply and demand. If people can't afford a drug, there isn't a market. And so we need a way, as countries, particularly in Australia and Canada, where there are government run drug plans, to look at the total cost of disease, and including the cost of drugs.

CHAIRMAN:

Thank you.

The next question is from Leah de Forest.

LEAH DR FOREST: Dr Bernstein, I was just wondering ? there's been increasing concern in this country about antibiotic resistance. How do you think this revolution in health research is likely to be able to address that or not?

ALAN BERNSTEIN: Excellent question.

Of course antibiotics has a proud history here in Australia with Florey.

Drug resistance ? antibiotic resistance ? is a perfect example of why we need health research.

Where are the next drugs going to come from and the next approaches to deal with bacteria, yeast, chlamydia, other parasites, other than through research?

They're not going to come from the sky. They're not going to drop out of the sky. They will come from understanding how bacteria and other pathogens interact with us, and exploiting that information to develop new drugs.

So in Canada there's a bright young guy from Vancouver who we fund who ? there's been big news in Canada that the water supply in a small



town in central Canada was contaminated with a strain of E. coli that caused I think three or four deaths in the last six months in Walkerton. And a young researcher at the University of British Columbia has been researching how that strain of E. coli actually adheres to the intestinal epithelial cells in our gut, and has developed an antibody ? a vaccine, if you will ? that targets that region. And he's now testing that vaccine as we speak. So it's that kind of research, and I could give other examples, that is going on in Canada, and I'm sure in Australia and around the world, that will lead to the next generation of 'antibiotics' (in quotes) ? whatever they may look like.

CHAIRMAN: John Kerrin.

JOHN KERRIN: Dr Bernstein, I might just ask you about an existing drug that we're having a debate about in this country at the moment, that these statins (or cholesterol lowering drugs). The US Institutes of Health said on May 15 they were being under-diagnosed in that country and were very important in the prevention of heart disease. We've seen the government actually cut back on them and suggest they should be used less and that doctors should be promoting lifestyle and diet. I was just wondering if there is a Canadian position as such at the moment?

ALAN BERNSTEIN: I can't comment because I'm not aware. I know there isn't a Canadian position, as such. And the

Canada ? the drugs that are paid for by government are done on a province by province basis, which has its own challenges. But I can't comment specifically on the statins ? sorry.

CHAIRMAN: Sue Dunlevy.

SUE DUNLEVY: Dr Bernstein, there's been a lot of coverage in Australian papers this week about something that happened back in the fifties in medical research when apparently the carcasses of stillborn babies in Australia were sent to the US for nuclear research. And there's been other controversy about the ethics that scientists apply when they go about their tasks.

Could you tell us a little bit about how you as a scientist approach ethical issues? How do you decide whether to do research on an embryo that's 14 days old or older or younger? What sort of moral code do you bring to the work that you do?

ALAN BERNSTEIN: Yeah. I won't give a personal answer because I think that in the end is not the right approach. In other words, I may be entirely ethical (and, believe me, I am) but why should you trust me?

I think there has to be, in research that involves humans, animals, whatever ? bodies other than myself that regulates what, you know, Alan Bernstein can do when he chooses to do research involving humans or human subjects or dead babies.

I read that story. And so in Canada there are, both at the local level, research ethics boards, at the institutional level whose job it is to approve clinical trials research, or any research involving human subjects. And those ethics boards are overseen by a national ethics committee that is an offshoot of the Canadian Institutes of Health Research. And so there's an arms length kind of overview of the ethical activities of researchers in the country.

In the end it's the host institution, the universities and hospitals, that have the immediate responsibility of enforcing our regulations and national laws and our power can be in the end to withhold funding if they aren't adhered to.

So I don't think this should be left up to individual investigators to decide what's ethical and what isn't. I think that's the national responsibility.

SUE DUNLEVY: [Inaudible]

ALAN BERNSTEIN: You're right. Quite often researchers make noises about jumping ahead. It's amazing actually in general (I am generalising) how much peer pressure there is in the research community not to do things like that, because if people jump ahead and society isn't either ready or doesn't want this to happen, it hurts all of us. It hurts the entire research community. And so there is great peer pressure not to do that. And in addition, you know, there is a



very famous case, certainly within the research community in the United States, of an individual who was doing gene therapy, had a company, and the company was providing the reagents to do the gene therapy; and a teenage boy, who was the subject, died.

The National Institutes of Health decided that that trial should not have happened, that it was premature, and that the researcher was in a conflict of interest.

So, that has had a ripple effect of sort of ? a damaging ripple effect, on hurting other gene therapy trials that are going on in the United States and elsewhere, unfortunately. And so it really behoves all of us as researchers I think to adhere to the national and commonly accepted ethical guidelines.

CHAIRMAN:

Doctor, I have the privilege from the chair of asking you the last question today. It relates to that. And it goes back to something you said a couple of minutes ago in talking about AIDS.

We surely are getting very close to the prospect now where there will be situations where the research and scientific communities can see a very distinct possibility of resolving a medical health problem through research which might be quite expensive. And given the state involvement ? the

government involvement ? at whatever level in our type of countries, what are the ethics of deciding whether or not to do that when there's not obviously a market?

ALAN BERNSTEIN: You're talking then about diseases where it either effects a very few number of individuals or it effects, for example, people in the Third World who can't afford it.

A huge problem. And again I made the comment in my speech that I think it's very important that as First World countries we don't ignore Third World problems. They can't afford to do it.

I think one reality to keep in mind is one of the exciting things about science is that very few diseases are one-offs, in a sense that what's relevant in cancer research very quickly becomes relevant to heart disease. And so to give, you know, a semi-example. Much of the technology in gene therapy that we were just talking about that is being used initially, prompted by understanding the genes that are involved in cancer ? that same technology may actually find its first application in heart disease. It may be eventually a mental illness before it finds its application in cancer. And so I think, you know, in brief, a rising tide raises elbows. And so I think as we advance in medical research in general, even the so-called orphan diseases will ultimately benefit ?

maybe not as quickly as they should, but they will eventually benefit. [Applause]

CHAIRMAN:

It's not exactly a birthday gift. But as a memento of the occasion, we'd like you to have this small trophy for your cabinet.

Thank you very much.

CHAIRMAN:

Thank you very much. [Applause]

* * **END** * *