CITIZENS' HEALTH CARE WORKING GROUP
WORKING GROUP PUBLIC MEETING

HEARING AND COMMITTEE MEETINGS

PUBLIC HEARING

City Hall
1221 SW 4th Avenue
Portland, Oregon

Friday, September 23, 2005
9:00 a.m.

PRESENT:
Catherine G. McLaughlin, Vice Chairperson
Frank J. Baumeister, Jr., M.D., Member
Dorothy A. Bazos, Member
Montye S. Conlan, Member
Therese A. Hughes, Member
Brent James, M.D., Member
Patricia A. Maryland, Member
Aaron Shirley, M.D., Member
Christine L. Wright, Member

HONORED GUEST:
Senator Ron Wyden

PRESENTERS:
Governor John Kitzhaber, M.D.
Dr. Michael Garland
Dr. Ralph Crawshaw
Ellen Lowe
Dr. Alison Little
Dr. Marian McDonagh
Diane Lovell
Dr. John Santa
Dr. Bruce Goldberg
Jean Thorne
Mark Ganz
A-G-E-N-D-A

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Jean Thorne
VICE CHAIRPERSON McLAUGHLIN: We've been waiting for Senator Wyden, and we've just been told that he on his way and will be here in a few minutes. So we are hoping to be about to start by 10:00.

In the meantime, I would like to welcome all of you for attending this listening session on behalf of the Citizens' Health Care Working Group. We have just finished field hearings in four citizens; in Jacksonville, Mississippi and Salt Lake City and Houston, Texas and Boston, Massachusetts. And at those field hearings we heard a lot about local initiatives and different things that are being attempted to try to improve the system, as well as people coming and telling us some of the problems that they as providers or as administrators or as patients have been facing within the system. We have used a lot of this information along with a lot of data that are made available about the health care system to produce a health report to the American people. We plan to have that report ready next month, and it will be distributed quite widely as well as on our website.

The point of that report is to really try to
explain to the American people this is where the dollars comes from, this is where they go, what is the flow of dollars and people in and out of the health care system. We are hoping by doing this that we will be able to begin a dialogue with the American people in which we can say, all right, now that we all have a better understanding of where that $1.7 trillion go and where all of the millions of patients go, where the millions of providers go, can we start talking about problems in the system from your perspective as well as solutions that you may have, desires that you may have for ways to improve the system.

In order to do that we are not only going to have surveys and we're going to have a website where people can come on line and give us ideas, but we're also going to hold community meetings all over the country.

We plan to start these community meetings in November or December. And we are certain that we will have at least one in Oregon, particularly those of us who love coming to Oregon, we're rooting let's come back to Oregon. So we've had a wonderful, wonderful stay while we've been here. Wonderful weather.

I know that Dr. Baumeister, who’s planned
this visit, organized to have the wonderful weather. We
give him total credit for that. And it really has been
wonderful.

At this point, though, we came here because
Oregon is the place to go in this country to find out
about listening to the American public about health
care, and giving us advice on what you learned when you
did this. And so, Dr. Baumeister and his staff have put
together a wonderful list of people who lived through
that experience to give us advice as we prepare to go
and listen to the American people.

So while today we're thrilled to see all of
you here listening, we won't be able to have an open
mike. We won't have an open community meeting. The
point of this really is for the working group to learn
from the people in Oregon who participated in that
process what they did right, what did they wrong so that
we do as good a job as we can going around the country
listening to people about their concerns and their
recommendations for the health care system.

So I'm sorry that we won't be able to hear
from all of you. I know that some of you would love to
be able to talk, and you will get a chance.
Unfortunately, it won't be today.
We're waiting for Senator Wyden to get here. He will be our first speaker. But in the meantime I wanted to thank Dr. Baumeister, who is a member of the working group, for getting this organized and for bringing us into this beautiful city hall that we've all been admiring and enjoying.

Thank you very much, Frank. And I think you wanted to thank a few other people.

DR. BAUMEISTER: Yes. Good morning, everybody.

I'm really influenced by the turnout here.

I have a lot of people to thank. You heard said it's not what you know but who you know, and I happen to know some people that really get things done.

I want to thank all the panelists for participating. Most of them are with whom I've had a personal or a professional relationship and I know their qualities. And I'm very happy to have them here.

I'd like to thank Senator Wyden for sponsoring this legislation along with Orrin Hatch. And I would invite you all to read the bill, because it's a rather remarkable bill that involves community, it involves it nationwide. And then the final report by law has to be heard by five congressional committees and
the President.

What they do with it now, we can't hold a gun to their head but we can put a fire in their feet.

I would like very much to thank John Santa. John is just remarkable. John put this entire panel together and all I did was say "John, would you?" And he said "Sure." And our relationship goes back about 25 or 30 years. And it's just been wonderful what he has done.

Jan Murdock, who works with the Foundation for Medical Excellence and for Governor Kitzhaber is also been instrumental in obtaining lodging for the working group and making arrangements that otherwise could just not have been made.

Lisa Rockhour who works with Senator Wyden's staff has been just really critical to this event.

And I would thank Commissioner Sam Adams and his assistant, David Gonzales who have opened City Hall to us and showed my friends here on this working group incredible Oregon hospitality.

And I'd also like to thank Legacy Health System who provided transportation for their shuttle buses for our group to and from my house last night for a dinner party that we held.
So with that, I'll turn it back over to Catherine McLaughlin, who did not particularly introduce herself, but she is an internationally known health care economist who has studied the uninsured and knows more about the uninsured than most people are afraid to ask. And she is an economist with a heart.

So, Catherine?

VICE CHAIRPERSON McLAUGHLIN: Isn't that an oxymoron?

Senator Wyden, we're glad to see you here. All of last week, some of you may not know that every time those of us who use MediaPlay hook onto it to listen to our music, we saw a picture of you, Senator, smiling on that computer screen. So you were in my heart all last week every time I did that. So it's nice to see you in person, and smiling. And we're looking forward to hearing your remarks.

Everyone in the working group has heard from Senator Wyden before, and I was very grateful to him as Frank said, for getting this legislation through so that we could go about doing this work. So we're eager to hear your remarks, Senator Wyden.

SENATOR WYDEN: Well, thank you, Madam Chair.
And welcome to all of you. You are really at ground zero in the effort to improve health care in Oregon and our country. We're a state of health care firsts. We were the first to come up with real home health care for older people. We were the first to figure out how you had to determine whether drugs were effective for people. We were the first to say that we had to make some hard choices in American health care. You couldn't be everything to everybody.

I want to start by just saying how thrilled I am that you're here and that your work is going forward. I know that you all have been working your heads off, listening to people around the country. My sense is you're firing off emails to each other at 2:00 in the morning. I hope folks understand that the members of the Working Group have full time jobs. They're not lobbyists or Washington insiders. They have full time jobs – including being doctors who take care of patients and advocates for people. I know that you've been drafting, redrafting, and drafting some more on the report that you're going to make public. And I hope folks understand that in doing so you're making history.

Never before have the American people been
told where the health care dollars go today. Health care reform in the past has been like telling people to get dressed in the dark. How do you do that? How do you find your clothes, let alone make the blue and the red match? I can't even do that when the lights are on.

Nancy Bass is here somewhere. She's given informed consent to marry me tomorrow night.

She was looking at some of your paperwork the other day and she said "I'm just amazed. I'm amazed at how hard this citizens' working group is going at this." She said "They are working so hard, I get tired looking at it. I'd like to sign everybody up for the citizens' leisure group."

And I think that is where I want to start. People are always asking me, "Well what are you up to? What is this thing all about?" And I say. "Well nobody's ever tried this before." And people almost always say "Oh, Ron, come on. People have been at this health care deal for years and years." But the fact is nobody's ever tried anything like this, which is to start it outside Washington, D.C.; get it out of the place where the lobbyists and the insiders can hotwire their deals that are favorable to them.

So nobody has ever done this, and it's to
ensure that there's public involvement. Then there is real political accountability with hearings and action after citizens of the country weighed in.

So in a few weeks you're going to be starting the effort to walk people through the tough choices in health care. And suffice it to say this isn't an exercise for the fainthearted. These are incredibly difficult choices and there aren't enough dollars to go around. And as you say in your draft, we're spending more than anybody else in the neighborhood. There's no one else in the world spending as much as we are on health care. One of the questions that I know you're looking at is how can it be that with wonderful doctors and hospitals and providers that our country runs 29th in terms of health expectancy, in terms of actual quality of life that people have? And I think the fact that you're going to try to help the country figure it out is a tremendous service.

I think the questions really are ones that you can't duck and get at the challenge that we started in Oregon almost two decades. I mean, we know we've got to do more in terms of health care prevention. We don't really have health care at all in the United States. What we have is sick care. We wait until somebody is
flat on their back in a hospital somewhere and say let's take care of them. And Medicare shows the craziness of all of this.

As you know, Medicare Part A writes some huge checks for some of these hospital bills. And the Medicare Part B won't write hardly anything to keep people well, keep them from getting sick in the first place. I think that's pretty bizarre even by the standards of Washington, D.C.

So, we got to do more for prevention, but there aren't unlimited dollars. So one of the questions I think is should we do more in the preventive area to try to keep people well even if it means we've got to take some of the dollars that now go for services for folks that have various illnesses? It's pretty hard to be Santa Claus there. That's the kind of tough question that I know has to be wrestled with.

The same challenge exists with end of life care. This was a tough issue before the Terry Schiavo case, and it is a lot tougher today. But the issue really is there when the best doctors and the best hospitals in the country tell us that they can't do anything to produce quality of life for the person and that's medically effective, we ought to have a debate
about what to do. Because we know that much of the health care spending in those last few months of somebody's life.

Another example is Medicare. You heard from the experts. Medicare is the fastest growing program on the planet: $3 trillion in liability. One of the questions I've been thinking about is why should Donald Trump pay the same Medicare premium as an elderly woman out here in southeast in one of the neighborhoods who's got an income of $20,000 a year, early onset of Alzheimer's and a big prescription drug bill? Not a very easy question.

That is a debate about transforming a huge really important social insurance program, but again an important kind of question.

What about the administrative part in American health care? The physicians on this panel can tell you. I heard Bill Clinton gave a speech two nights ago and said 35 percent of the health care dollar goes to administration. I don't know if he's right. I don't know who is right. I know you're wrestling with it. But I don't think that there's a provider around and certainly scores of consumers who can't tell you the system is choking on paperwork and forms and bureaucracy.
and red tape.

Tax policy -- We're spending more than $100 billion because we've made the judgment back in World War II that health care should be tax exempt for the employer and tax exempt for the worker. We spend more than $110 billion on that. I think we ought to have a debate about whether that's the best way to spend the money.

I'd wrap up this section in terms of questions by saying I do not pretend to have the answers to the questions that I just posed. I wouldn't possibly come before a group like this and say that I do. But I do think that the public wants somebody with your independence, your credibility and your expertise to ask those questions so that they'll have a sense that people like yourselves with your independence of judgment are going to try to drive this debate rather than people in Washington, D.C.

Usually when health care reform gets stuck in the nation's Capitol, all the powerful lobbyists sit where all of you are. They're the ones who almost always find a way to get a seat at the table. What is unique about this is this time they're locked out. The law was written to do that. No members of Congress can serve.
No lobbyist gets to serve. You were the ones who got to fill out all the forms and make sure that you have essentially what amounted to an ethical colonoscopy; the Government threw the rope up here and said all of you are independent and credible. And that's why we're looking to your leadership.

I'd especially hope that the urgency of all this can come through. We've had some discussions about, and your Chair today, Catherine McLaughlin, makes this point very eloquently, that people are told that the sky is going to fall before, and we don't have enough money and western civilization is going to come to an end if you don't act. And people have heard that before. But there are some forces at work today that have never been present before. For example, we are experiencing a demographic revolution.

On New Year's Day, January 1, 2007 we ramp up to more than 15 million baby boomers retiring. We have never had that before. They're going to need a lot of health care. They're going to expect a lot of health care. It's a driving force we've never seen before.

We've never had technology that pushed us to the brink of immortality. We're not there yet. We're kind of pushing our way up there, and the whole country
is now wondering how to make the best use of these
wonderful devices and products.

    My sense is we have never had a bigger gap
between the amount we spend and what we're getting in
return. We spent $1.8 trillion last year; more than
$6,000 for every man, woman and child; that is about
$25,000 for a family of four.

    You could go out and hire an internist,
who'd make over $100,000 a year and would do nothing but
work for a handful of people, a family.

    So all of those forces are different than
what we saw in the past 60 years as the country has
wrestled with this from Harry Truman in 1945 and the
81st Congress all the way through Bill Clinton, and
everybody else. Our citizens want you to show us how we
can right this wrong.

    Now today I think you're going to get a
whole lot out of hearing from some Oregon pioneers. I
call them pioneers because they merely start the whole
effort to say “Look, in health care you can't do it
all.” There's some difficult kinds of choices that have
to be made and no matter how much money you spend,
there's never really enough. They were led by the next
speaker, Dr. John Kitzhaber.
And what Dr. Kitzhaber really taught us, and I think when you write the history of American health care it's going to be a big big deal, is the decisions about health care are going to be made one way or another. But what Dr. Kitzhaber told us is they're going to either be made in the front door with the public involved and a real debate about the choices or they're going to be made in the backroom and they're going to be made without the public involvement. The fancy word in Washington is called "transparency." That's the new big, you know, buzz word. Everything's got to be transparent. But you and I know it's about the grassroots; it's about whether the public is going to be involved.

So essentially what Dr. Kitzhaber and our Oregon pioneers started close to 20 years ago was something that was really built around this public involvement. They made the judgment that I know you're looking at that health care is kind of like an ecosystem. Everything is related to everything else. And I think that's a critical concern as well.

And, frankly, as I look back on it, maybe the pioneers will tell you other things, including things we could have done differently. My sense is we
didn't really ask for enough. Dr. Kitzhaber and I have talked, and I have urged this with our state leaders. I'd really like to see states go to the Federal Government and say "Look, if you people aren't going to get this health care thing right, let us take the dollars home. Let us take the dollars home. Give us waivers. Let us go out and do our own thing. Bring the stakeholders to the table; the laborers, business and seniors and disabled folks and minority and let us make our own decisions."

There are a bunch of things that I think that we probably would do over again if we have the chance to do it. But I think the points that were made then; got to make choices, got to do it in a public eye and that health care is not just about dollars but it's about values. It's about the things that are really important to you. Those are inescapable truths. And those pioneers, in my view, really got it right.

Now I mentioned in the beginning that Oregon was a state of health care firsts. I just want to mention what I think the firsts are about your work and the Citizens' Health Care Working Group.

For the first time with your leadership, the national government is trying to improve health care
with a bottoms-up effort starting outside of Washington, D.C. rather than going top down with people in Washington trying to drive it.

Second, nobody's ever been told where the health care dollar goes before. I know that sounds astounding. I've mentioned it to people and people say "You know, I just wish I could just to one place and have somebody tell me where the money goes, where all these programs are." So my understanding is, and Dottie has mentioned this, you're talking about a definition sheet where you just tell people in plain understandable language, here's what Medicare is, here's why it's different than Medicaid. Here's this thing called SCHIP. You know, all of us who talk about health care rattle off SCHIP. I don't think most people on the planet know what it is, probably they think it's something for their TV set or something. But, as we all know, it's a plan for poor children, especially after Katrina.

So in telling people where the money goes, we should be treating health care like an ecosystem. Certainly after the debacle of '93 and '94 people stopped treating health care like an ecosystem. We kind of got it piecemeal; a little piece here and a little
piece there. Boy, does that cause you problems. Congress passed a prescription drug bill this year. I voted for it. I still have the welts on my back to show for that. But towards the end of the debate, out of nowhere, people said well if we had this government program for seniors and prescription drug coverage, maybe the employers are going to drop their coverage. Nobody wanted to do that. Certainly don't want to discourage employers. So Congress without any debate, without any hearings, without any discussion, said let's spend $60 billion -- $60 billion -- on helping employers keep their coverage. Nobody ever asked once, “Was that the best use of $60 billion dollars?” Boy, you can buy a lot of health care in this country for $60 billion, serve a lot of people. And nobody ever had that discussion because health care isn't treated like an ecosystem anymore.

So the first time our national government is going to make it convenient for people to participate, what you're talking about going online and offline where somebody can show up in their office or a senior citizen center, type into the computer and get a sense of what some of the choices are. That's a real service to people.
For the first time our government has said that after the public involvement there's got to be political accountability. And I wanted to come and tell you that in particular Senator Hatch and I have got your back on this. We sit on the Senate Finance Committee. The law has been written so that this isn't about another public opinion poll. This isn't about people just jabbing about health care a little bit and then going home.

When you're done, when the citizens have been heard, the law states that Congress and the President must act. They've got to quickly move not to talking about what they're interested in, but what you come up with. There have got to be hearings in the Congress quickly while it's fresh in people's minds about what the citizens want in America on health care.

So that's a lot of firsts. I'd wrap this up simply by way of saying that together I think we can figure this out. I think that the American people want to think through health care for themselves.

And I am tremendously honored to represent our state. I never thought when I came to Oregon to start law school that someone like myself, a first generation Jewish guy with a face for radio would have
these opportunities for public service, or the
opportunity in particular to serve on the Senate Finance
Committee where could I make the extraordinarily
important work that you're doing really count.

I think the country is ready for this, folks. If you walk people through the choices, if you
arm them with the facts, if you ask tough but important
questions in language resembling English so that it is
not health-speak, I think people are there. I think
this time we can do it right. I think this time together
in a partnership we can do something that we should have
done a long, long time ago, and that's to get health
care that works for all Americans.

(Applause).

VICE CHAIRPERSON McLAUGHLIN: Thank you very
much, Senator Wyden.

We can take a few minutes for questions
before we move on.

I just wanted to thank you very much for
that talk. Everyone on the working group appreciates
your enthusiasm about not only this group, but health
care in general. And in the spring when you came to
talk to us at our first meeting you warned us that this
was like a trek through the Himalayas. And certainly
after these last few days of hard work here in Portland, we needed this energy boost that you just gave us. So we're very grateful to you for coming here because it has been hard work. And we really appreciate your enthusiasm and your reminding us of what you and Senator Hatch put into that legislation which, hopefully, a year from now will make a big difference. So thank you very much.

Did anybody want to ask Senator Wyden some questions? I guess not.

SENATOR WYDEN: I've never heard this group so quiet.

VICE CHAIRPERSON McLAUGHLIN: I haven't either. I don't know. I'm not sure.

PARTICIPANT: It's not a question. I'd just like to thank you for bringing out the disabled community. I feel very welcomed here in Portland. I think this is the most disabled people that I've seen participate so far. I think this is an important contribution and effort.

SENATOR WYDEN: I think you've made your point.

I don't know where he is. Where is Commissioner Sam Adams?
VICE CHAIRPERSON McLAUGHLIN: He had to step out, but he was here earlier.

SENATOR WYDEN: This is really the people's happening. I mean, it's not really freedom unless everybody's free to have a chance to participate. And just as we thought that the law that we wrote would liberate health care, what we want to do is liberate public involvement, not just for people who can spend a lot of money and make long trips as you said, Montye. But people who can see that government is more accessible and convenient to them.

We're glad you're here.

VICE CHAIRPERSON McLAUGHLIN: Thank you again, Senator Wyden.

SENATOR WYDEN: Well, thank you.

VICE CHAIRPERSON McLAUGHLIN: We also want to wish you and Nancy the best tomorrow. We've been told tomorrow's weather is supposed to be picture perfect, so you're starting off on a very good note.

SENATOR WYDEN: Was that part of your --

VICE CHAIRPERSON McLAUGHLIN: Probably.

Thank you very much.

Next we're going to hear from Governor Kitzhaber. The Governor is a former emergency
physician, a legislator and two term Governor of the State of Oregon. All of you know this, but this is being part of the formal record.

He is the past President of the Oregon State Senate where he authored and implemented the ground breaking, as we will hear more about, Oregon Health Plan, now in its tenth year.

His legislative career, which began in 1979, was marked by active leadership in the areas of public education, community development, environmental stewardship and a wide variety of health care.

In January of 2003 Dr. Kitzhaber began serving as President of the Estes Park Institute, which conducts six annual educational conferences for community hospital.

And I must say I heard Governor Kitzhaber give a talk about the Oregon Health Plan at a conference this spring in Princeton, to which he got a standing ovation. It was wonderful, wonderful information, and I'm looking forward to hearing you share that with the full working group here today.

Thank you for coming.

GOVERNOR KITZHABER: Thank you very much.

For the record, I'm John Kitzhaber.
First let me say what an honor first of all it is to have been asked to participate and to contribute to this tremendous work that you're doing here today. And I want thank Senator Wyden, and certainly Dr. Baumeister for helping to put this together, and all of you for the fine commitment that you've made to what is a very very significant undertaking.

I also want to extend my personal thanks to Commissioner Sam Adams who, along with his staff, worked day and night to arrange meeting rooms, to take care of logistics to make this work. So I’m very grateful to Sam and his staff.

I noticed from the screen up there that my battery isn't fully charged. It ought to be Health Care That Works for All Americans Group. I think you might consider calling it the Health That Works for All Americans Group, a point I'm going to come back to in a minute here. I think we shouldn’t confuse health with health care.

Before I start I just want to add to the urgency, the sense of urgency that Senator Wyden indicated in his remarks today. I don't think we have time in this country for incremental change. We need
change of truly revolutionary scope if we want to get ahead of this problem. And to illustrate that I want to use the words of Denis Hayes, who is the Executive Director of the Bullitt Foundation in Seattle, who puts it this way. "Zeros matter. A million seconds ago was last week. A billion seconds ago Richard Nixon was resigning from the White House. A trillion seconds ago was 30,000 B.C. and humans were just beginning to use stone tools."

Our national debt is $7 and a half trillion and it is escalating as the population ages. And while Congress is preoccupied with the solvency of Social Security, the real problem is Medicare. The Social Security gap is around $5 trillion; big but with retirement -- actually not even the retirement. You don't even have to retire. When my generation turns 65 the unfunded liability in Medicare exceeds $60 trillion. That's the magnitude of the problem that is rapidly overtaking us. And it means that we've got to act definitively and very boldly.

I was asked to provide an overview of the Oregon story, if you will, one state's effort to try to develop a more rational and accountable framework of the allocation of health care resources. And I'd like to do
that by trying to offer a personal perspective on the Oregon Health Plan, about why it came about, some thoughts on the larger context in which it was developed, and also some lessons that can be learned both from its successes and from its failures.

So for me the story began in May of 1986 when I was serving my first term as Senate President. And during the interim, after the legislature had adjourned, we had a budget deficit. And about half of it was due to increased case loads and utilization costs in the Medicaid program. So in order to comply with our constitutional requirement to balance our budget, the State Emergency Board took a number of actions to bring the budget back into balance, one of which was to change the eligibility standards of the Medical Needy Program and to disenfranchise 4300 people from state health insurance coverage.

And I remember being astonished at how easy it was. We were in a hearing room and spring was happening outside. And we looked at some numbers on a piece of paper and took a couple of votes and the budget was balanced. But also with the stroke of the pen we dropped 4300 people from financial assess to the health care system.
And, of course, at the time none of us appreciated the fact that we were in, in fact, rationing people. It was just a sterile budgetary exercise. But it was disquieting. And unlike the other members of the Emergency Board I was a physician. And I went back to my emergency department and five months later I began to see a few individuals in the ER who had lost coverage because of that sterile budgetary exercise five months earlier. And in most cases they were people who had delayed seeking treatment for minor problems because they were concerned about how they were going to pay for it. And in one case it was a middle aged man who had suffered a massive stroke because he had been unable to access his blood pressure medications over the preceding five months.

And that had a profound effect on me and what happened subsequently. And that sustained that disquiet I had felt when the Emergency Board had disenfranchised these 4300 nameless, faceless people. And I realized that they weren't nameless, faceless people. They had names and faces and hopes and dreams of their own. And this wasn't just a sterile budgetary exercise. What we were doing by balancing the budget in that way was to disenfranchise other people from access
to the health care system, with very real human consequences. We simply didn't have to be accountable for them.

Now the next year in 1987, the Oregon legislature voted to discontinue Medicaid funding for major organ transplants, at the time, an optional service. And there were some rational reasons that they did that, which we can discuss later if you like. The point is it was an explicit social rationing decision, and it was totally uncontroversial and almost unreported by the press. Probably because there was no one who needed a transplant there at the time the decision was made, something that was soon to change.

So the legislature adjourned in June. They used to actually adjourn in June. And in November a 7 year old boy named Coby Howard showed up who had acute lymphoblastic leukemia and needed a transplant. His family was covered by Medicaid and the program no longer covered that service, so his family turned to the public.

Throughout the media now this problem was played out on the nightly news and on the front page of newspapers and the media fanned the public emotion to a fever pitch while completely ignoring, in my view, the
larger policy issues that surrounded this tragic situation.

I remembered watching a very premature infant die very quietly before my eyes of respiratory distressed syndrome while I was an intern. And the cause of his death, which essentially was lack of prenatal care, was not as dramatic and apparently not as newsworthy as dying for lack of an organ transplant. But I can tell you from personal experience that it was no less tragic because it was simply not reported.

So on Wednesday December 2nd Coby died at Emanuel Hospital in Portland. This was indeed a very real human tragedy. But it was also a sensational human interest story and local and national media descended upon Oregon, although they had totally ignored the decision to cut the program a year earlier. And in the wake of that publicity there was an effort mounted to partially refund the transplant program, for it was eight or nine people; the people who had applications into the program at the time. And I opposed that motion.

The media saw this as a debate about transplants; I saw it as a debate about how we allocate limited public health care resources. So to me the question wasn't whether transplants had merits, clearly
they often do. The question wasn't whether the state could afford eight or nine more transplants; it could. The question to me was simply this: If we're going to spend more money on the public health care budget, where should that next dollar go? What was the policy that would lead us to fund transplants as opposed to further expanding access to prenatal care? Is one more important than the other? What was the policy that would lead us to offer transplants to eight people as opposed to 18 or 80? Where was the equity in taking a group of poor individuals who had access to a fairly good Medicaid benefit package and adding transplant coverage for a few of them while ignoring 20,000 or 30,000 people, also deeply impoverished, who had access to nothing?

And what became clear is that there was no policy. There was no policy whatsoever.

And while we could easily have funded another eight or nine transplants, we had no way of knowing or being accountable for the consequences of not spending those resources on other individuals in Oregon who were deeply in need and excluded from the system altogether. And it was precisely this lack of accountability in the way in which we allocate our
public resources for health care, which we were trying to address with the enactment of the Oregon Health Plan.

Now to understand the nature of the Oregon Health Plan and also the lessons I think it has to offer to this working group, I think it's necessary to review the underlying structure of the U.S. health care system in which all state reform efforts must necessarily take place. And I think this is important because you're not about changing the health care system in Oregon here. Your charge is to make a recommendation about how to change that larger U.S. health care system which influences everything we do at the state level.

I think that the single major structural flaw in the U.S. health care system is that it was built around the concept of categorical eligibility rather than around a commitment to universal coverage which means that in order to be eligible for publicly subsidized health care in America, unlike public education in which everybody's eligible; in order to be eligible for publicly subsidized health care you have to fit into a category, and those categories were established with the enactment of Medicare and Medicaid four decades ago.

Now the enactment of those two programs with
the existence of employment private-based coverage left the U.S. with a public/private health care financing system with two major arms. A private arm, primarily employment-based coverage, as you know. And then the public arm, which is essentially Medicare and Medicaid. But because the system was developed around a concept of categorical eligibility rather than commitment to universal coverage, a growing gap began to develop between the public and private arms of that system. And in that gap were people who don't fit into a category, if you want to look at it that way.

They're not 65, so they're not eligible for Medicare. And they don't meet the income or categorical eligibility requirements for Medicaid. They don't have work-based coverage and no one will insure them in the private individual insurance market.

Today, as you know, there are over 45 million people in that coverage gap, including 600,000 people in this state alone. And a gap exists because we've organized our system around categorical eligibility rather than around universal coverage. And we have therefore avoided explicitly answering as a society a very fundamental question, which every other industrialized nation in the world has answered in some
form or another. And that question is simply this: “Who has the responsibility to pay for the health care needs of citizens who can't afford to pay for it themselves?” And because we've never answered it, we have to allow the economic market to make the decision for us. But economic markets are designed to make a profit, not to foster social responsibility. So it shouldn't come as a big surprise that no one goes out and competes to take care of people who can't pay for it.

Why is that so surprising? In fact, in our market oriented terminology people who have a payment source are referred to as market share. And we compete for them. And people who don't have a payment source are referred to as liabilities. And we avoid seeing them through adverse selection and through cost shifting.

Now if you think about it, the ability to cost shift serves as a pressure valve in our system and it also reduces the accountability and thus the political pressure needed for needing full reform. And you know how it works.

People who don't have coverage, who find themselves in that coverage gap, eventually many of them get sick enough and go to the emergency room where
federal laws require that they be seen and treated. And then the uncompensated costs are simply shifted back to both the public and private third party payers through incremental increases in their insurance premiums and their bills.

Now those third party payers then seek to shift the cost back on the individual. States do it by manipulating income eligibility to reduce the number of people who are on Medicaid; it's what we did in 1986. Employers either drop coverage altogether, which is a steady trend, or they increase co-payments and deductibles that shift costs on to individuals who at some point can no longer afford to pay for their health care services. So they've actually simply increased the number of people in the coverage gap, they go back to ER and the cycle is repeated.

It was this cycle, this vicious cycle, and the implicit rationing that goes along with it that we were trying to address with the enactment of the Oregon Health Plan.

Now, as I mentioned earlier during that two day debate over the transplant program, I kept asking myself if we're going to spend more money in the public health care budget in Oregon, where should the next
dollar go? And, of course, the answer to the question depends on what you're trying to accomplish with the allocation. So is it the objective to ensure that all citizens have access to the health care system, or is our objective to ensure that all our citizens are healthy? It's not the same thing at all.

And I think that our objective is or certainly should be health rather than simply the financing and delivery of health care. My point being this: Health care is a means to an end; it is not an end in itself. It has no intrinsic value outside its relationship to health except as an economic commodity, which is pretty much how the current system treats it. And, of course, that's a large part of the problem.

So clearly, access to some level of health care is necessary for individuals to remain healthy. Yet the fact remains that not everyone has the financial access to pay for their health care, which gets us back to the question of who has that responsibility.

So what we tried to do first and foremost in the Oregon Health Plan besides clarifying our objective was health not just financing and delivery health care, was to try to answer that question of responsibility by establishing that the state would assume responsibility
for financing health care to the poor, which we defined as anyone with an income at or below the federal poverty level.

Now, in retrospect, particularly given the rise in health care costs, you could argue that that was way too low. You should have established it at 150 percent or 200 percent of the federal poverty level. But the important aspect of this decision is that it represented a clear rejection of the principle or concept of categorical eligibility.

We believed that the sole criteria to access publicly financed health care, at least for the Medicaid program, should be financial need, not merely a set of categories that were created four decades ago and that excluded poor men and poor women without kids who were pregnant, no matter how impoverished they might be. That made no sense to us. We couldn't find any way to justify it.

And of equal importance was the fact that we proposed to establish that eligibility criteria in statute to make it hard to change, thus removing one of the major tools of the implicit rationing by the legislature, who was simply manipulating eligibility.

Now, by clearly defining the public sector
responsibility, and that's why I think if the nation were to say we're going to have universal coverage, we're going to assume that responsibility, you significantly shift the focus of the debate of eligibility to benefit -- from who is covered to what is covered.

I mean, my God, in Medicaid there are 28 different statutory eligibility categories. Do you know how much money we spend trying to discern which are deserving and which are undeserving? It's a nightmare. It makes no sense. It defies common sense. It defies logic.

So if you can shift the focus of the debate from the eligibility to benefit, then instead of debating which individuals should receive funding for which services, and by implication which individuals should be denied those services, we would instead ensure that everyone had access to the health care system and then we would debate the funding priority established in each specific service available.

So as a consequence, establishing priorities to an open and explicit and accountable process became the centerpiece of the Oregon Health Plan, and it's based on a clear eyed recognition that we were dealing
with public resources, and that public resources are
ultimately finite.

States, unlike the federal government, can't
push their hard fiscal choices into the deficit to allow
our children to deal with. Most states have a
constitutional requirement to balance the budget, which
means that since we can't spend all of our resources on
health care at the expense of education and public
safety and infrastructure, the amount of money available
for health care in public budgets is ultimately finite.

And what does that mean? It means that
health care rationing in some form is inevitable. If
the amount of money the public sector can spend on
health care is limited, then people who depend solely on
that source of revenue to finance their health care
needs will face some limitations on what will be
financed. And it's our job to embrace that reality and
to make the process explicit so that we can ensure that
that level, that that floor is adequate and meets the
health care needs, and thus the health of all of our
citizens.

And there's two ways that health care can be
rationed, as we've discussed earlier. You can ration it
implicitly or you can ration it explicitly. And today
because we have no explicit policy of universal coverage in this country, most of our rationing is done implicitly by dropping people from third party insurance coverage. That is the most insidious, impersonal kind of rationing. It's based on no policy whatsoever, and it is utterly devoid of any type of accountability. It's very much like high level bombing: For the people who are responsible for the decisions, never have to see the faces who suffer and sometimes die because of their choices. And let me give you a tragic case in point.

In February of 2003 the Oregon legislature, to balance the budget because of the recession, discontinued prescription drug coverage for the medically needy program, an implicit rationing decision very similar to the one that I participated in during 1986, and the result was every bit as tragic. As a consequence a man, I guess he was in his mid 30s, named Douglas Schmidt, who suffered from a seizure disorder was no longer able to access the medications that managed his seizures. So he was still eligible for state coverage, but the program no longer covered prescription drugs.

After about ten days he went into a sustained grand mal seizure, suffered serious brain
damage and ended up on a ventilator in a Portland hospital, where he remained in the intensive care unit for a number of months. He was eventually transferred to a long term care facility where he died in November of 2003 when life support was eventually withdrawn.

Now the cost of this anti-seizure medication was $14 a day. The cost of his intensive care unit visit exceeded $7,500 a day. A total cost of over $1.1 million, all of which was simply billed back to the state. So the legislature didn't save any money through this implicit rationing decision. In fact, it increased its fiscal liability, and in order to deal with it, had to drop more people from coverage perpetuating this kind of human tragedy and fiscal disaster.

So my point is simply this: In this country of ours, we're going to pay these costs one way or another, unless we're willing to let people die on the ambulance ramp if they don't have health insurance coverage. And I haven't heard anyone propose that we do that. So we're going to pay the costs either explicitly or implicitly. And by refusing to do it explicitly on the front end, the cost is much, much higher both in human and in fiscal terms.

Think about it for just a minute. Douglas
Schmidt died of budgetary and political expediency based on a policy that says, in effect, we won't pay a few dollars a day to manage a seizure disorder in the community, but we'll be happy to fork out over a million dollars to sustain you on life support once your seizure condition had destroyed your brain. It's a policy that says we won't pay pennies to manage blood pressure in the community, but we'll pay for the cost of your stroke in the hospital when you have it. It's a policy that says we won't ensure that all women in our country have access to good prenatal care, but we'll be happy to pay the costs of resuscitating your 500 gram infant in a neonatal intensive care unit. And that should not be acceptable to any of us. Any of us.

The Oregon Health Plan was based then on the premise that if publicly subsidized health care has to be rationed, then it has to be done explicitly, it has to be done accountably, and it needs to focus not on people, but on benefit levels based on their relative value and effectiveness in producing health. And that in turn required that we be able to establish priorities through the creation of a framework for evaluating the effectiveness and the appropriateness of the health services being purchased.
So to carry out that responsibility we created the Oregon Health Services Commission. It consisted of five primary care physicians, a public health nurse, a social worker and four consumers, one of whom served as the chairperson. And through an open and transparent process, specific services and treatments were prioritized according to their clinical effectiveness and based on our determination for value. So there were things like, just to oversimplify it, appendectomy for acute appendicitis or penicillin for bacterial pneumonia; conditional treatment.

Physicians were used to provide the necessary clinical information as well as the literature search. And thousands of volunteer hours for Oregon physicians have gone into the development of this priority list. And then the determination of social values was through an extensive public outreach process. And you'll be hearing more later this morning both about the Commission and its work and about our public outreach process to help integrate social values into the privatization process.

The first priority list was completed in February of 1991 and it consisted of 709 of these condition treatment areas that were originally in the 17
categories. So the categories, the 17 categories, were prioritized on the basis of our interpretation of the social values and within each category, the condition treatment pairs were prioritized on the basis of the expected outcome and benefit and duration of that benefit.

So to give you an example, services in the highest category were treating an acute fatal condition where treatment saved your life and returned you to your previous health state. Everyone agreed that those definitely needed to be treated.

Because of the high value placed on prevention by the participating members of the community, the category maternity care, including prenatal care, natal care and postpartum care, ranked very high, as did preventive care for children.

Because of the value of compassion, hospice care was also ranked very high.

And at the bottom of the list were categories for services of self-limiting conditions, services that had little or no effect on health status, and what we defined as futile care, which was less than a five percent five year survival rate.

And that final priority list was given to an
independent actuarial firm that determined the cost of providing each element on the list into a managed capitated reimbursement system. And that list, along with its accompanying actuarial data, was given to the Oregon legislature.

Now the legislature was statutorily prohibited from altering the priorities as established by the Health Services Commission. Reimbursement had already been determined by the independent actuary and physicians and hospitals had input into the actual list. So the two major tools of legislative rationing implicitly had been taken away; cutting provider reimbursement rates arbitrarily and changing eligibility. So they simply had to make the resource allocation decision, which by its very nature is political.

So they looked at the existing Medicaid budget and saw what kind of benefit that you could gain with that, and then the debate was on how much more money you want to pump into the system and to get a benefit level that we felt was adequate and defensible. So in that way the definition of basic care or what is covered was directly linked to the reality of the fiscal source, which hopefully it is if you remove all of our
implicit ways of avoiding the confrontation with that reality.

Now before I conclude and comment very briefly on the lessons that we learned from the Oregon Health Plan and on its ultimate fate, I want to just say at this point that the same principles around which the Oregon Health Plan was built are also reflected in the Health Resources Commission and its work that you're going to be hearing about here later this morning. So equity, transparency, explicit decision making, accountability, value, the use of evidence continue to be the guiding principles for the Health Resources Commission and also for the Center For Evidence-Based Policy at the Oregon Health & Sciences University in its continuing work of evaluating through a systematic review of the evidence of various classes of prescription drugs that was first started by the Health Resources Commission under the leadership of Dr. Frank Baumeister, who was at the time the chairperson.

Now let me simply conclude my comments this morning on the Oregon Health Plan. If you recall, to implement the program required waivers from the federal government, because the plan violated Medicaid law on a number of levels. And we can come back to that if you
have any questions, because I think that is a key element in leveraging future change in the larger health care system.

First, we wanted to be establishing our covered benefits through the use of a priority list rather than through the existing mandated Medicaid services. And it's astounding, if you think about it, why we should have to get a waiver to actually build a way based on what works and what doesn't work in health. Nonetheless, that was one of the areas that we had to get waived.

The second one was we wanted to cover all Oregonians below the federal poverty level, not just those that fit into categories. So there were some 90 or 100,000 new eligibles; there were the poor men, the poor woman, kids who were pregnant that we wanted to cover and still keep our federal matching dollars.

So we were first denied our waiver request in August of 1992 by the first Bush Administration. We were finally granted our waivers under President Clinton in March of 1993. And the Oregon Health Plan was implemented on February 1, 1994.

After a ten year run, during which time over a million Oregonians benefited from this program, the
Oregon Health Plan was largely dismantled in 2004 after the legislature in effect eliminated coverage for the new eligibles who came into the program under the waiver. Since then, over 60,000 Oregonians have lost coverage. Since that time I'm sure more will follow, and unfortunately it is moving back to the old system of categorical eligibility and implicit rationing and huge cost shifting that the plan was originally designed to address in the first place.

Although you'll be hearing more from other speakers about the history of the Oregon Health Plan over the last decade, I want to take just a moment here at the end to touch on three major lessons that I think it has taught us. Hopefully, they'll be relevant to the work that you folks are about.

These are lessons I think that we learned both from the halcyon days of the plan but also from its ultimate demise.

The first lesson is that it has taught us that it is possible to develop a clinically and politically defensible priority list and to use that list to establish a covered benefit based on that list.

The second lesson is that it is possible to confront the reality of fiscal limits and to assume
accountability for the difficult choices which those limits made inevitable. You can do that and actually get reelected. But perhaps the most important lesson, and I think this is the one I hope you really take home, is that meaningful reform cannot take place in my view unless the basic structure of the U.S. health care system is revised. Unless we are willing to openly challenge the underlying premises and assumptions on the way it should be built.

The demise of the Oregon Health Plan was not simply due to the recession and the budget deficit. It was also due to the larger system in which that health plan existed. So the fact is that we were trying to bring about meaningful reform in the constraints and contradictions of a fatally flawed federal structure. This is not a state problem. This is not a Medicaid problem. This is a national problem and it is a system problem, and it cannot be fixed at the state level without fundamentally changing the structure in which all state reform efforts have to exist.

How long do you suppose Microsoft would last if Bill Gates held on to a ten year old operating system or a five year old operating system, or one that's two years old?
We're clinging tenaciously to a 40 year old health care operating system and we wonder why we can't solve the health care challenges of the 21st century. What we have been doing up to this point is nibbling around the edges of a very serious social and financial problem. Modernizing Medicaid is not the same as challenging the basic structural assumptions on which those programs have been built.

Certainly there are many poor elderly citizens in this country and in this state who need and deserve publicly financed health care. But there are millions of poor children and working adults who need and deserve exactly the same thing and today who are entitled to absolutely nothing.

(Applause).

My hope is this working group will provide the leadership necessary for the United States Congress to realize that it is time to stop defending programs at the expense of solving problems. And that we cannot successfully meet the challenge that this crisis poses by continuing to allow our thinking and our reformed efforts to be constrained by a 40 year old eligibility and financing structure that reflects the realities of the middle of the last century.
Thank you very much.

VICE CHAIRPERSON McLAUGHLIN: Thank you.

(Applause).

VICE CHAIRPERSON McLAUGHLIN: We have some people standing to applaud. Thank you very much for that information.

When you say that it's important to ask what works and what doesn't work in producing health, as Frank announced, I'm an economist, so this is language that I deal with all the time. And it's a way of thinking, a conceptual framework that is very familiar to me.

I'd like to point out, however, that the statute has charged this group not with coming up with a list such as that, but going out and talking to the American public and saying, what's one of the four questions we've been asked to address is, what services do you want provided. So my question to you and then we'll have some time to have other members of the group ask you some questions, how do you think that tension should be balanced between what the American public say these are the services that we want provided in the U.S. health care system, this is what we want to be part of the system versus what experts would tell them these are
the services that at the margin issue, as you said, are
worth the extra dollars; that you get something for what
you pay? How would you recommend that for us to go
about our charge in the next six months to balance that
potential tension?

GOVERNOR KITZHABER: I don't think you can
balance that tension unless you put cost in the equation
and also answer the question who has paid that cost.
And I'll give you just a real quick example, and you
heard a little bit of it.

I think what's really in contention in this
health care debate is the allocation of public resources
-- who benefits from that allocation. I don't think
we're really arguing about private resources. The
people who can pay for their own health care aren't the
system problem. It may be too high, they may not like
it, but they're not the system problem. What we're
really concerned about is how you allocate those public
resources.

And right now, you know, we basically
believe in this country that death is optional, right.
It's not a part of the life process. It's optional and
we're encouraged in that belief by modern medicine.

Dick Lamm, former Governor of Colorado,
tells about the study on death rates he did all over the 
world, in the U.S., in Uganda, in Argentina, in Bolivia, 
and he found an interesting thing; it's all the same, 
one per person.

So we've basically built a system of health 
care that maximizes benefit one individual at a time, 
but we increasingly rely on public resources to pay the 
cost of that care. And there's nothing wrong with that 
if people are paying the cost of their own care. But 
we've created something that can be Gerhardt who is 
tracking the comet, where basically we're requiring to 
finance health care for individuals at the expense of 
common resources. And a lot of people aren't in that.

It's simple. You have to be able to ask. 
You have to have a framework of which you can ask, is 
that marginal benefit that we're paying for one person 
coming at the expense of thousands of other people who 
can't even get into the system. That’s exactly what we 
were debating with Coby Howard.

So I think if you asked people what they 
want in a health care system, they'll pretty much tell 
you everything. And that doesn't get us down the pike. 
The pike is to ask yourselves how are we going to 
finance it, how are we going to assure that there's
social justice, but that there's equity in the way we allocate those public sources.

You know, people with more money will always be able to buy more health care, more cars, more everything. There's nothing wrong with that. The real problem is that we're subsidizing those extra expenditures with resources paid by people who don't have access to the system.

It's a two-sided entry. You can talk about what you want, you also have to talk about how much it costs and who is going to pay that cost. I don't think you can avoid that.

VICE CHAIRPERSON McLAUGHLIN: Brent?

DR. JAMES: I have a relatively complex question about this. While I've been interested for a very long time as I followed your work, I spent a lot of time in other countries, particularly Sweden, Australia and Canada looking at the way that they ration care. It's done through government policy. It's done largely out of the public view. I want you to tell me about the politics of this in a particular way, because I think that's one of the key issues.

First, in the idea when you say explicit rationing, you've implied that so let's make explicit,
again explicit multi-tiered systems. Minimum two tiers
where some people have one level of services and others
have the private funds to buy something buy that. In
that context the medical industrial complex is only
appropriate where people who want access to the public
funds because it so greatly expands their market and
they stand to make an awful lot of money from it, who
often times work in conjunction with people who aren't
making a lot of money but have very strong personal
beliefs, strong social justice. So you have kind of the
moral push of the social justice and the money push of
the medical industrial complex.

So I just wanted you to comment some on the
practical politics, can we do this explicitly and what
are the politics of making it happen explicitly in the
world? Can we face that issue as a people and how would
we go about doing that?

GOVERNOR KITZHABER: Well, the first part of
it, I believe you can do that. I believe that's
essentially what we did in Oregon.

I recall Dr. Jackson on the front page of
the San Francisco Chronicle and Newsweek and it was a
very unpleasant two years after this business, but I
went on to get reelected to the Senate by 60 percent and
Governor.

I think people are willing to hear the truth if we tell them. People know there's a problem here, but you’ve got to create a framework. You keep creating a real framework, people have great choices. When you lose your job, you don't tell one of your kids they can't eat. You allocate your resources differently. So people I think are capable of doing it. The challenge is to have political leadership that talks -- that tells us what the choices are and creates a framework where they can engage. And I think that's really what we did through the Oregon Health Plan.

We have the prioritization process where the Health Services Commission didn't terminate the benefit. They simply said based on the framework you gave us, here's what the priorities can look like. The legislature had to make the allocation decision. It was political. It was explicit. They were ultimately accountable to the voters. And you can see exactly what you covered and what you didn't cover. So I think it's possible to do that.

Someone once said there's no survival value of pessimism. You know, if we're unable to come to terms with that, we are going to allow our future to
become a matter of chance rather than a matter of choice. Because the cost of this animal is going to overwhelm us all. And in fact, the stability; it's a huge issue.

Could I just add one more. Maybe -- I hope I've tried to answer your question. And if you want to talk about specifics, I do have an idea how to go about this.

But I just want to say one thing about rationing. And I'll give you a personal story. My son injured his spleen a while back, and ended up in the emergency department of one of the local hospitals. And I was sitting there thinking two things, while I watched them with the IVs and the wonderful cardiac monitors and the things that literally saved this little boy's life.

To get to that hospital I drove through a section of our city that's very, very poor. And I couldn't help but ask myself how can they have so much health care concentrated here and so little health four blocks away. Where women can't get prenatal care, where kids don't get immunizations, where young people get shot or where we're losing people because of the neglect and substance abuse. That's a huge contradiction that we need to think about when we talk about rationing. We
need to talk about what the system is currently doing.

The second thing that occurred to me is my mother is 88, very frail and was in to see her physician and she had a high sed [??] rate with a nonspecific indication for inflammation, one of the indications of a neoplasm tumor. The workout in her case would have involved an endoscopy and colonoscopy and a whole lot of things that she had no desire to have done. We would have paid for all that, by the way.

The doctor said let's check her blood work in a few weeks and see how she's doing. I said why? I said if you're going to continue to check the blood work on an 88 year old woman who has decided she doesn't want a bunch of treatment -- you know, why do it because you're going to continue to find abnormalities and you're not going to change the outcome.

What my parents want is to stay in their home. $18 an hour it costs about for in-home care to allow them to stay in their home. Medicare doesn't pay for that. But it will pay for an MRI, CT scan, a cardiac bypass, a transplant and it makes no sense.

So when we talk about rationing what we need to ask ourselves is what we're rationing compassionate? Is there a health associated with it? And I think the
answer is clearly no. And I think the way you deal with it politically, is you've got to somehow tease that out. It doesn't have to be the way we did in Oregon, but you have to tease it out so it's not just hospital services and doctor services. You have to be issuing treatment or something where you can actually see what you're buying. And I think there's a perfect opportunity then to take the next step, which would be to, let's say, take those conditions that are core rate or chronic conditions and do a real evidence based review to see if there's any evidence to support how we're managing those things and to move best practice schemes. And I think there's a way to do this that will save money -- I think there's more than enough money in the system so we don't deny any American the treatment of services for effective and appropriate care. I believe that further, and it's a matter of how you reallocate them. And I think the explicit nature of that will help survive the political process.

VICE CHAIRPERSON McLAUGHLIN: Well, I have to be the person of bad news, but I'm afraid we have to end at this to try to stay on schedule.

You've been wanting to drink that water for a long time. Thank you very much.
(Applause).

VICE CHAIRPERSON McLAUGHLIN: Next we're going to be hearing from Dr. Garland. Dr. Garland is professor emeritus of the Department of Public Health and Preventive Medicine, the Oregon Health and Science University. He is also a senior scholar at the Center for Ethics and Health Care where he has served on the faculty since 1978.

He received a bachelor's degree in philosophy and letters from St. Louis University and a master's degree in theology from the University of Notre Dame (at the University of Michigan, we don’t like to talk about them too much, they just beat us again in football).

He earned a doctorate in religious studies from the University of Strasbourg in France where he focused on the theory of responsibility and ethnics, obviously something very important to this working group as we're starting.

Dr. Garland has been active in the field of biomedical ethics since 1973. He's published widely in the field of biomedical ethics. And he co-founded the Oregon Health Decisions in 1983 to foster public participation in development of state health policy.
DR. GARLAND: I think we should stop there. I want to introduce Dr. Ralph Crawshaw who is the co-founder of Oregon Health Decisions and who is a --

VICE CHAIRPERSON McLAUGHLIN: Two for the price of one.

DR. GARLAND: Yes. Since that time we've been somewhat joined at the hip. And so we thought it would be best to try to put these thoughts together hearing from both of us as we walk through them.

VICE CHAIRPERSON McLAUGHLIN: That's fine. We also do in fact welcome Dr. Crawshaw, who is psychiatry [?] of public health and, as you said, you've been joined at the hip which must not be very comfortable but seems to be productive.

So we welcome your comments and looking forward to hearing from you as we face our difficult journey along ethical issues.

DR. GARLAND: Dr. Crawshaw has been a mover and shaker in Oregon health policy for many years and that's how we first came together with Oregon Health Decisions was thinking about the role of the public in that health planning system, at which time he was the Chair of the Oregon Coordinating Council. And shortly after we began working together, we were interviewed by
a reporter from the *Wall Street Journal*, who after hearing about many of the interests that Dr. Crawshaw had and the things that he had done to try to improve health care in Oregon, said "Ah, now I recognize you. You are a natural born buttinsky." He won't leave things alone that need to be fixed because of the suffering going on.

I gave you a kind of outline that I will briefly talk from, it's some slides. I want to go quickly through those so that you have a chance to have some interchange, especially around what can be done in terms of public participation.

Oregon Health Decisions was founded in '82. Its whole point was to foster public participation and access to discourse around the health care system of what it could be doing and should be doing.

There were a couple of projects prior to 1989 that showed support for the underlying ideas of the Oregon Health Plan, which was not a success for everybody. And a sense of difficult decisions needing to be made. And the public ought to be involved in those hard decisions.

In relation to the Oregon Health Plan we worked prior to that with then Senate President Dr.
Kitzhaber who chaired one of our project's steering committees on access issues in health care looking forward to the 1990s. And as the Oregon Health Plan took shape both in his mind and the political arena, we met with him and I see the former Executive Director of Oregon Health Decisions at that time, he and Tim sitting up there. We had a chance to meet with Dr. Kitzhaber and talk about making sure that the public input had community meetings, not just hearings. That there's an opportunity for discourse that's horizontal as well as vertical up and down the power lines.

And since the Oregon Health Plan was formed and launched we have sat in follow up public engagement programs to look at issues and fallout from the Oregon Health Plan, and that includes three random sample telephone surveys in 1996, 2000 and 2004 all of which have reasserted in particular a strong widespread and persistent commitment to Dr. Kitzhaber's theme, universal access being a fundamental fixture or value that has to be fulfilled. And a notion that we should be rationing the services that available, not the people who get access to it. That's the core thing that has really gotten through Oregon. And that cost awareness and personal responsibility were an important part of
this.

In relation to the Oregon Health Plan, we have 47 communities statewide. The idea was to be geographically and demographically comprehensive. Over a 1,000 people participated. There were 12 statewide public hearings, the traditional public hearing with people testifying. And 1500 people participated in those.

And there was a telephone survey using the quality of well being scale to try to get at quantitative judgments of the values that people would give to certain states of well being. Ultimately that one got set aside in the wave of process. So as Paul Starr in his wonderful book on Transformation of American Medicine reminds us that when we start down the path of a dream of reason, something rational, we have to take power into account. So power will always be there.

The structure of the Oregon Health Decision's community meetings was to establish some focus. And we always felt we could get people out for maybe a couple of hours in the evening, but not for all day meetings and the like. That if you really want to get participation, you have to put it into the lives of
people. SO we would have a brief focus on the issue. We used a 20 minute slide show. We had an exercise in which everybody there was divided into small groups where they made individual judgments about some scenarios in health care. Then they discussed the values that were embedded in those individual judgments.

And then the values that emerged from that discussion were accumulated for the whole group to see. And then from all of those 47 meetings there was further accumulation of those values into a standard list that was forwarded to the Health Services Commission.

Several kinds of values were identified. And I really want to stress this as you think about your community meetings.

There were some health values; prevention, quality of life, keeping people alive, making sure mental health and chemical dependency are provided for, and having the ability to function. That those were all health outcomes that were very important people.

There were economic values that folks thought of when they thought of what makes health care important to them. And that was that the treatment be effective. We won't to buy things that were -- and that it be cost effective. That if two things both work, we
should get the most cost effective of them.

There were a number of social values that emerged. As soon as you talked about what's important in health care, you can see that we used the health care system to achieve some social values like equity, like the fact that it might benefit many people. So the benefit spread around. The personal choices and important social value impact on society. The exercise of personal responsibility for one's health and community compassion.

Prevention and community compassion actually provided the Health Services Commission with a couple of highs because they weren't on the list of diagnoses and procedures that they were using. Prevention wasn't really there. And the people all talked about prevention being very important to them. And so the Prevention Services Task Force, U.S. Finance Task Force lists were used.

Community compassion focused on the fact that we can't always cure, but it's very important to stand by somebody who is suffering and dying, a lot like Dr. Kitzhaber's reference experience. They want to live in their life comfortable -- live in their home comfortably and not just be out chasing another health
care treatment.

I note on here that there are lots of methods of participation and you want to fit the methods to the goals of the outreach. And those goals are to gather information, which I think you're charged to do. But also to build a constituency, a political constituency and to educate the people. And I think all three of those goals are working in your projected activity. And you want to shape the methods of those community meetings to achieve those goals. And it is a real design problem.

We have found in our work over the years of 20 years now that a focus on values is really important. And so if you think about what health care services people want, answering that first question, I would urge you to try to frame it so that it moves into valued outcomes rather lists of specific services. And we learned that people are much more aware of valued outcomes and describe those and talk intelligently about those, but will be quite confused about specific services because they need more paths than their priority disposal.

The data from the input is going to be both qualitative and quantitative. And I think you want to
have both. And I was delighted to hear you say earlier that you're going to be using some surveys as well as community meetings. And I think that's important since surveys allow you to gauge the distribution and the intensity with which opinions are held.

A couple of things on decision phases from a good colleague of ours, Dr. Gary Anderson who is a cognitive psychologist. That at the front end of problem structuring, I think that's what you're charge is is to help structure the problem for Congress and the President to deal with this, you want to distinguish facts and values so that it's very clear who you're going to ask for the right information and get values from the public, approach experts about facts and probabilities. And the policymakers have to weigh the alternatives. So there's work that just can't be taken from the policymakers and the public outreach can't substitute for that kind of work either; yours or later on Congress and the President.

Just a final note about something we have learned about public participation over the years is that there are real constraints. In fact, it always has to fit some political process. And so you'll be designing this around the political process that you can
hope for.

Timing has got to be right.

There's a level of concern. So we have a level of concern, but I think it's important to be able to play into that level of concern in America, the 46 million uninsured Americans who are worried about where they're going to get their next health care.

And then the understanding of the issues. And it appears that you aimed at that, but you want to glean out some better understanding of the issues and a framework that you think will lead to intelligent discussion.

And bear in mind and be patient, and persistent with the barriers. That we have a kind of a weak sense of community. Our intense individualism leaves our sense of community rather weak. I think in health care we operate on some illusions about health care being a private individual commodity rather than a mutually provided service.

Alienation from politics is extreme and cynicism is rampant. And all three of in part increase dragging on the effort that you're going to be working on.

And my final slide is just a summary of what
we've learned. In public participation you really want to bring together two things: Messages from the public that say this is what's important to us and messages from experts saying this is how we get the most of what's important to us. And that final point of pulling together is that work of policymakers.

Thank you for your time.

I want to get Ralph to comment on some of his ideas around this, and also that he can field any of your questions.

VICE CHAIRPERSON McLAUGHLIN: Great. Thank you very much.

Dr. Crawshaw?

DR. CRAWSHAW: We're a real team, the two of us. And I thank you for the privilege of speaking to you.

I'm reluctant to be here. I'm reluctant in speaking to you for two reasons. One is it -- the Governor of going to give you the technical part of what's happening. The other reason is how much I envy you. I personally envy you.

If your experience is anything like the experience I had sitting in those seats at the state level instead of a federal level, I can tell you it
changes you. You will be a different person. Now why is 
this? Because you are in a position to uniquely see the 
vision of America's future. You people are going to 
listen, not to radios, not to TVs. You're going to 
listen to real people. And once someone comes and 
testifies before you and says I didn't have the money to 
get the medicine for my child and my child is deaf, 
you're going to be a changed person because you're 
responsible to see that.

Let me give you an example of how shocking 
this can be, your position. We had a Oregon Health 
Decision meeting in a county which we were going to 
review what the reactions were to some of our findings.

Incidently, Frank looks worried there. I 
should make sure that you understand this is not a 
patient/doctor relationship where he may get sued by me. 
Because he's my doctor and I'm his patient.

We had a meeting at the county and the word 
got out that the AARP was going to show up and critique 
what we were doing. And I sat in a seat similar to the 
seat you're sitting in. And the representative from the 
AARP got up and he said "We, the senior people in 
Oregon, do not wish any improvement in our health care
that comes at the expense of children." Let me tell you, that was unexpected. And that was a view of America's vision.

So, in talking in this way I want you to know that my life has changed. It was changed in terms of my capacity for compassion. When you hear that person suffering in front of you and you're not allowed to say "I feel your pain." What you're going to have to do is say "I live your pain."

And when it comes to the whole business of judgment, you're going to be up late at night wondering just where should I come down on these issues. It's a personal decision and I have to make that decision. And that's very difficult to do.

And lastly, the thing that you are not prepared possibly to know is that you have to use willpower. You have to use conviction. You have to make it in words and in print, and in your behavior that you believe that you are right in speaking for all the people who spoke to you.

Now I'd like to close with an ancient parting from the Greeks. And they had a way when they left each other to say be strong, grow stronger, be ever so much stronger.
VICE CHAIRPERSON McLAUGHLIN: Thank you. What better than Oregon to comment here about what we're facing? Thank you very much for that.

I'm going to let other people ask some question. I know some of us are responsible for the community meetings, and I suspect they want to get some wisdom from you, some response.

We'll start with Aaron who is Chairing our Community Meeting committee.

MR. SHIRLEY: If you briefly describe how you organized and carried out a typical community meeting.

DR. GARLAND: Yes. It's one of the slides. But we always start with a need to focus the attention of the people who have come to a meeting. I mean, I'll get into the meeting but most of the work goes on before the meeting starts. That's recruiting. So we used everybody we could to get into the local networks: The county health departments, chambers of commerce. One of our major partners in all of this was the Oregon Health Action Campaign with Alan Kenny as the leadership who has a wide network. So there's an effort really to get people into the room with enough demographic mix that you can have a fruitful conversation.
And then assuming that we have 30 or 40 people in the room, we would have four tables with no more than 10 chairs around it because we want to build small group discussion into this horizontal conversation.

So we have a focus. We have the room laid out so that that small group discussion can occur. And we have an exercise that causes people to make a judgment about the health care system, the services that they want. And then we -- actually we tell them, and we lead those judgments on the floor because what we want to really get at is the conversation that occurs when it says well why do you want newborn intensive care covered as an extremely important thing and why do you think if it's okay if we can get that, and get at the values that underlie those judgment.

And then after a period in which, say if it's an hour and a half meeting, after a period of a half hour to 45 minutes of small group discussion, we will take reports from each of the tables so that we begin to accumulate the core values that have been discussed at the table.

We have put at every table a training facilitator who will keep the discussion moving and who...
will make that report.

That effort we used to call a graffiti wall, but what it does it allows everybody in the room to take ownership of the ideas and to see whether their table was like other tables and whether they're inspired or given a fresh idea about what came up at one of their tables.

The end of the meeting all of those things on the graffiti wall are reviewed publicly by everybody. They get a chance to say well that's really not what we not meant or that reminds me, here's another thing I want to get into this discussion.

That is accumulated and sent to a central office that's pulling all of these values together from all of the millions and refined into a manageable list, which was the 13 values that I showed you on the slides.

DR. CRAWSHAW: There's another element to all of this, and that is it costs money. And what we did I went to -- I'm a member of the IOM. And I know, who was at the time the head of the Robert Lee Johnson Foundation. And I had discussed what we were doing. And he felt about it about favorably, and he said he could give a presidential grant of $100,000 to help us, but he wasn't going to do. Instead what he did was he called
two local foundations and told them they'd better give
us each $100,000 or he wouldn't give us any. And that
gave us $300,000 to be able to take care of some of the
important things.

MS. MARYLAND: Patricia Maryland from
Indianapolis, Indiana.

Dr. Garland, after you synthesized the
information, the data, how were you able to take that
information and work with the policymakers to be able to
create the Oregon Health Plan and the components that
made up that plan? And the second part of the question
is and how were you assured that those individuals who
participated in those community meetings felt as though
their voice was heard?

DR. GARLAND: Well, we always had a
feedback. I'll answer your second question first. So
that everybody who participated in the meetings got the
report that went to the policymakers so that they saw
what was happening.

The question about how do you make sure that
the policymakers are paying attention, that's all front
end stuff. We've developed a kind of biological lingo of
talking about the receptor site, which is the
policymaker. And we want to make sure that the receptor
site wants to receive this hormonal input of public information and is able to do it, and is planning to do something with it.

So a lot of I think the continuing work of this working group is getting a sense of how to express what comes out of your labors in such a way that the policymakers are ready to hear about it. So that I think you need front end conversations.

We always have those with Dr. Kitzhaber starting with and the staff, but also as the Health Services Commission was created, we worked hand-in-glove with them. And the Health Services Commission, which was the receptor site for our input, provided the chairperson of the steering committee of this public outreach. So that there's an intertwining from the beginning. And that I think is a crucial way of making it important.

To encourage you, we -- but even though we struggled to get people to come, it's hard to get people to come out. And somebody pointed out to me years ago that the problem is health care is everyone's third most important issue and that there are other things and displace it. So it isn't always the first thing on the mind of everybody on the street.
But those who came invariably stayed afterwards. We almost had to shoo them out of the room. And expressed great gratitude to be asked and involved in these kind of meetings. And it gave a weight to our calling of the meetings to be able to say authentically and truthfully at the front end the reason you're here for this conversation is that somebody who has their hands on a health policy lever is listening and is committed to hear what you have to say.

VICE CHAIRPERSON McLAUGHLIN: Okay. Montye.

MS. CONLAN: I just wanted to talk about values. I'm interested in the community meetings and it sounds like you were able to accomplish getting both qualitative and quantitative data with one session. Do you feel that the quality of that data on both sides is equal? And that also the policymakers, did they review both the qualitative and quantitative with equal interest?

DR. GARLAND: Actually, we didn't get qualitative and quantitative at each of the meetings. We got qualitative at the meetings. They ran sample surveys, telephone surveys done independently. So I think you have to go after those separately. And what you want to do is try to coordinate the focus of them
enough so that they eliminate each other. And that the
qualitative information will give you insights into the
problems, help you stretch the problems. The
quantitative always allows you to say we heard this at
the community meetings. I wonder how widely distributed
that is. So I think you get them by separate paths.

How do you express them so that policymakers
pay attention, that they're important to them? Or
actually which one did they listen to most?

MS. CONLAN: Well, were they receiving them?

DR. GARLAND: I think that they -- actually
what happened was that the qualitative data was allowed
in the federal waiver process. The quantitative data was
disallowed. So that the Commissions knew of the
quantitative results, but had to look at those
qualitative results. So they said this set of insights
is what we will use to structure the logic of our
debates as they moved through some other process.

So the qualitative data turned out to be
very important and very useful.

DR. CRAWSHAW: One of the outgrowths of the
Oregon Health Decision's movement was American
Decisions. This was 17 different states that came along
and did this. And in the course of that the Kellogg
Foundation had me go around the country to help start these things. And I can tell you, it is the qualitative information that starts the meeting. Quantitative may end it. But in North Carolina, there was one woman there who was just afire with wanting to get health decisions for North Carolina. I asked her what's your motive. She said "My father died in such a terrible way that at his death bed I swore I would never -- never cease to prevent it from every happening to anyone else again." That's qualitative data.

VICE CHAIRPERSON McLAUGHLIN: We have time for one more question from Dottie and then we will take only a ten minute break instead of a 15 break because we're trying to get sort of back on time.

MS. BAZOS: Well, thank you very much for coming. I think I have what I think is a very big question. We need to let the whole of the United States know that we exist, that we're here to listen. And we have a long period of time in which we're going to be going to little pockets of the United States. We obviously can't go to every community.

We will be asking for public input on the web. We will be using whatever types of tools we can develop to get that input. But my questions to you are
how on a national scale are we really going to get ourselves in the newspapers so that people know who we are and really in a very genuine way. I don't think any of us want to sell anything. What we really want is input. We want the public to know that we're serious about this. But I think what I'm having trouble grappling with is how we are going to then help the public know that we've taken their input seriously, because they may need us.

We may have a website that says tells us what you think, tell us your story. How do we get back to them? How we will keep them engaged through the long term? Because this is just the beginning. You know, we have a long term engagement. We need to keep them involved. Can you help me with that?

DR. GARLAND: It is a constant problem. I think getting ready you really need to invest in a communications campaign and you recognize the reality of a communication campaign, that people will pay attention that you're going to go into their neighbors.

MS. BAZOS: Right.

DR. GARLAND: And so you've got to focus that and you're not going to be in every little town in American and so you know what neighborhoods and states
you're going to be in. And I think you really have as one of your tasks is to create this communications outreach so that you have reason to believe that the word is out; newspapers, both the television and radio and the like.

How you stay in touch with them and afterwards I think is trying to get sufficient reports of a meeting when it has occurred and then making sure that everybody who comes to those meetings are is willing to give their name, address and/or email gets feedback from you at the various stages in which you produce a report. So if you're going to have an interim report and then a final report, that they get that delivered with them and with it a note saying "Thank you. You helped create this."

MS. BAZOS: Did you build some of the reports as you went along so that people saw what was happening?

DR. GARLAND: From every meeting we sent notes in email and I think a hard copy back to people who had been at that meeting saying this is the report from your meeting.

MS. BAZOS: But did you accumulate those reports so that when you went to fifth report, did you
say now we've been four and this is what is coming up.

DR. GARLAND: No. There was that meeting and then the final report.

DR. CRAWSHAW: The other point that I'd make is very important. And Senator Wyden made this one. You should identify yourself with the political leader of people. When we worked at Bend to talk to the people in Bend, we had the mayor of Bend introduce us.

When you go to X, Y and Z, find out what the political network has as the star performer. And if you've got that endorsement, they know that speaking to you is going to echo to where something's going to make a difference.

So it's that validating your position to the Congress is so important.

DR. GARLAND: Just one last thing. I think that the statement that was made earlier today by Senator Wyden saying that he and Senator Hatch intend to keep legislators and the congressional feet to the fire is a promise that you ought hold him to and that you ought to be able to promise the people that you have meetings with. Because otherwise you'll run into the cynicism of saying, you know, what good does it do to hold this, this is just more gum flapping and nothing
ever happens. So the drive to say this is intended to be an action item and that you and the Senator and others are intending to make that happen. And I think that's an important message to be able to get out. It keeps their interest.

But things are going to happen. You know, hurricanes will come along and other things will displace and focus on the 46 million uninsured.

Thank you very much for your time.

VICE CHAIRPERSON McLAUGHLIN: Thank you very much.

We'll reconvene in ten minutes for the next session. Thank you very much.

(Whereupon, the meeting recessed for a break.)

VICE CHAIRPERSON McLAUGHLIN: We need to start our next session. It's always wonderful to see everyone so stimulated that they want to keep talking and want to interact. And I wish we were able to take a longer break, but we really can't or we'll run into a crunch at lunch and we won't be able to continue to afternoon.

We now are going to continue hearing about this issue of prioritizing benefits and how the Health
Services Commission can make these kinds of decisions. And first we're going to hear from Dr. Little. Is she in the room? Oh, great. Wonderful. Gee, I thought we were going to start.

Dr. Little is a family physician from Lake Oswego. After initially practicing in a small town in central Oregon, she shifted her interests to public health and administration receiving her MPH degree from the University of Washington in 1998. She spent seven years as Medical Director of a fully capitated health plan in central Oregon and served as Commissioner on the Oregon Health Services Commission from 1996 to 2002.

She's here to, as I said, address even further how we go about prioritizing benefits as we go along in our community meetings and make some of our suggestions. And we welcome your advice and from your experience in doing that.

Thank you very much.

DR. LITTLE: Thank you.

The Health Services Commission was created by legislation passed in 1989 with the following directive: Report to the Governor a list of health services ranked by priority from the most important to the least important representing the comparative status
of each service to the entire population to be served.

Prioritization was initially based on the ability of the treatment to prevent death, the lifetime cost of treatment in equivalent cases, and set of values derived from public meetings across the state that you just heard about. These values included such things as a higher priority for maternity and preventative care and a lower priority for limited conditions and those without effective treatment.

Today the prioritized list is a ranking of 710 condition treatment pairings. I have a sample set of lines in your hand out for the record. Each line includes one or more related ICD9 codes as well as CPT treatment codes that define the appropriate treatment.

In addition to the codes, many lines also have guidelines attached which serve to further specify under what conditions a diagnosis or treatment is covered.

The Commission, as you heard previously, consists of five physicians, a public health nurse, a social services worker and four consumer advocates.

The work of the physician commissioners, who comprise the health outcomes subcommittee, includes both the mundane and the controversial. Every year both ICD9
and CPT codes are added and deleted and modified. And these changes must be reviewed and recommendations made for incorporation into the list.

In addition, the subcommittee reviews action on new technology and considers changes to the list suggested by providers, enrollees and advocates who believe that a service should be prioritized differently.

In 2003 the Commission responded to requests for a more evidence-based approach by creating an algorithm for evaluation of new technology. I've included that in your handouts as well.

Some of the changes the Commission has to consider are quite minor such as adding more specific diagnoses codes or a procedure that was inadvertently left off. Others are quite controversial. Sometimes that controversy is external and the Commission has remained remarkably united. In other cases there was a little spotlight but the Commission itself was divided.

And I'd like to give you an example of each of those.

The first situation was exemplified by the need to incorporate the Oregon Death With Dignity Act which was passed into law in 1997. Although the Act was completely unrelated to the Oregon Health Plan, it still
represented a health service available to the population and making it necessary for the Commission to consider it. They were charged with deciding whether and where physician assisted suicide should be placed on the prioritized list.

After hearing hours of public testimony and in front of an audience of over 100 people the Commission voted ten to one to add this service to the comfort care line of the prioritized list. They were unanimous in their belief that services available to the general population of Oregon should also be available for those on the Oregon Health Plan. The lone dissenting vote was from a consumer advocate who was concerned with the law that the law was discriminatory against someone who was so disabled they could not self-administer the medication and be unable to take advantage of it.

In the end, I believe this public debate provided reassurance that many voices were heard and helped everyone involved to understand the issues better.

I do need to make clear that this service is funded strictly with state dollars and no federal monies.
Now let me give you an example of when the Commission experienced some discord. This occurred when they considered the addition of a stem cell transplant to the breast cancer line also in 1997. Preliminary clinical trial results showed improved outcome for women with advanced breast cancer, but all the randomized control trials were still in progress.

Several lawsuits had been filed across the state to force private insurers to cover this treatment, and the Commission sought legal advice regarding state liability in the event of such a suit as well as the implications of covering experimental treatment which was prohibited by rule.

Ultimately stem cell transplant was added to the breast cancer line by a five to four vote but with very strong dissension from the opponents.

During the time that I served as Commissioner I was a medical director of a fully capitated health plan in central Oregon. In my role there I had intimate knowledge of how the list worked and daily contact with providers about it. Often times we would identify oversights which I would then forward on to the Commission for their review and action.

Occasionally they disagreed with the
placement of a particular condition. But in my role as Commissioner it was always helpful to be able to explain the rationale and the limits of the plan.

Perhaps most illuminating in my seven years as medical director despite being the bearer of bad news regarding the coverage of a condition on many, many occasions I never once heard a physician say that they thought that the concept of the prioritized list was a bad one. And I believe that it is this strong support both from the public and from providers that made the plan as successful as it is.

And I think Ellen would like to speak next and then I'll take questions.

VICE CHAIRPERSON McLAUGHLIN: Thanks. That's wonderful. Thank you.

Next will be Ellen Lowe, who is a consumer advocate. She's a seasoned participant in the processes of government including the legislative process. She has served on many decision making groups related to health care, and retired in 1999 as the part time Director of Public Policy for Economical Ministries of Oregon and continues to serve as the legislative advocate representing the Oregon Food Bank, the Oregon Law Center and United Way.
So thank you for joining us, and we look forward to hearing your comments.

MS. LOWE: Thank you. It's my pleasure to be able to participate today.

The Health Services Commission had actually been in existence for nine months when 15 years ago, and I'm now the veteran on the Commission, our Governor asked me to join it. I was very aware of the difficulties in expanding health care access for poor Oregonians, for I along with many other stakeholders was the server as that first computer run emerged. And I'd like to say that the stakeholders that were there with me during those first nine months, it's amazing how they continued through the whole process and still are watching us. But there are folks in this room today who were there 16 years ago and they maintain their interest from consumer groups, from providers and some -- those that I sometimes refer to as "The suits."

Now I had also been an observer, though, of the legislative session during the previous three sessions. And I began to be aware of the real shortcomings of the traditional Medicaid program as I heard some very tragic human stories. The system was broken. And in my work stories of the human and
monetary costs of the lack of access to timely, appropriate health services was also frequently shared.

Now, some individuals and groups feared that this new approach would endanger the category for the eligible. They weren't very confident that two birds in the bush wouldn't fly away. And so they came to our meetings, they came those listening sessions that Mike Garland describe. They asked questions, we responded. They educated us. And I truly believe that the openness, the responsiveness and the leadership of the process built trust. And so, in fact, those local health advocates for people with special needs became the activists with the national group, their counterpart.

I appreciated often being able to be part of those conference calls.

Now my life gave me access to many individuals with poor health status, but I also spent some time reaching out to folks I thought wouldn't come to an official hearing where it would come the attention of a helping agency. And I do not believe I was unique among the Commissioners in this informal fact and value finding.

For example, I went to several laundromats on Saturday where I tried to engage young families in
conversation about health services, what their needs were as they were waiting for their clothes to dry. Now, granted, this wasn't a very scientific approach, but it really broadened my understanding of the time pressures on young low wage families. These were the ones least likely to go to some of these other groups.

And I found out that for them it just wasn't what the benefits are but when and where they are available.

I'd like to highlight several services that I do not believe would have their current placement without citizen requests. And this was particularly true of general care. It had not been part of the adult Medicaid program, so we really heard from them.

We also heard from the working poor. And when asked why dental was not considered a medical service, I was always hard pressed to come up with an answer that satisfied me, let alone them. Our Commission really would have ignored the public if dental care had been bypassed.

Another area was mental health. Tradition in both the private and public system called for a continued separation. The public didn't, nor did many primary care physicians. Their belief in the efficacy
of the integration of mental and physical health services advanced the practice. But institutional barriers, in my judgment, still keep it from full integration. And in Oregon the documented community costs when the Oregon Health Plan standard population, those are the new eligibles, lost mental health services, serve as a reminder that anything less than integration is penny wise and pound foolish.

Now our comfort care line in the very beginning evoked discussion about the meaning of healing. In my age group I've long heard criticism of futile, expensive and sometimes painful care in the last months of a terminal illness. And families at our meetings, both at the Commission and those that Dr. Kitzhaber and Dr. Garland talked about, they questioned why there was financial support for aggressive care but there was no assistance for palliative.

Palliative care does not come, though, without some additional costs. And they were seeking just modest help for patient choice.

With the current acceptance of hospice, it seems so strange that just a few years ago this choice rarely received any governmental assistance and often no health insurance support. Our definition of healing had
to be expanded, and as it was we began to see changes in
private insurance plans as well.

Now, I used to go to the outcomes meetings,
the ones where the physicians worked on those condition
treatment pairs in order to more fully understand health
conditions and treatments. And as the physicians shared
their findings and the views of the physician panel, I
was impressed with the depth of their knowledge. But I
also heard them acknowledge the need to seek more
information.

Now the lack of data couldn't become an
excuse for closing down our project. But rather it
became the impetus for periodic review of the condition
treatment pairs and for stimulating more research such
as is taking place at OHSU.

Now I do not recall using the term evidence-
based medicine 15 years ago. But that really was what
we were about, and it is what we are still plan. The
Oregon Health Plan by its very nature is a work in
progress.

I believe the strength of our project is the
success of using community based coordinated plans,
managed care if you will, for the delivery of clinical
and ancillary health services. For the unorganized I
have come to know so well and for the time constraint working for it, these plans work with neighborhood clinics so that there can be extended hours, a simplified access and participation and specialists. And to me very importantly they've worked with other community based groups to coordinate access to other vital support services, the kind of activities and services that create a healthy community. They are a community resource, and I truly believe that the Oregon Health Plan is a national resources as well.

And I thank you.

VICE CHAIRPERSON McLAUGHLIN: Thank you very much.

(Applause).

VICE CHAIRPERSON McLAUGHLIN: As I said, it was actually our recognition of the leadership shown by what Oregon has done that led us here to this meeting. And I already can tell you that the members of the working group have expressed to me how grateful they are for all of you today coming to talk to us. We've learned an enormous amount.

We have time for one or maybe two questions from the working group. I think everybody's seeing lunch in the future.
MS. HUGHES: Hi. I'm Therese Hughes, and I'm from the Family Clinic in Los Angeles, California.

One of the things I wanted to ask you about was in terms of provision of specialty services under the plan, if patients need specialty services do you have a problem with -- I guess in LA, one of our many health care problems is that we have a network of clinics that work very closely together to serve as a medical home for all of our patients. But specialty services is something that is severely lacking. And I wondered if there was a way that, you know, you came upon something that through this process that allowed entrance of specialty services into the arena of care for these underserved populations?

DR. LITTLE: I think we achieved that mostly through the heavy use of managed care. About 80 percent of Oregon Health Plan members are enrolled in a managed care organization and they are required to ensure access to specialty care.

MS. HUGHES: And I just follow up with that? What about the wait time? Is there --

DR. LITTLE: Well, I haven't been in that position for a few years, but my perception is that it has gotten more difficult in the last few years. And I
know Oregon has limited to some degree the decisions that they are making.

As far as accurately, of course it depends on the specialty.

MS. HUGHES: Right. Right.

DR. LITTLE: It is somewhat of an issue, but I think perhaps less so than in other -- managed care.

MS. HUGHES: Okay. Thank you so much.

MS. LOWE: And could I just interject, that I think one of the things we did well is that the panel of specialists who assisted us with information in putting together the list, we involved the specialists. And so I think many of them sort of accepted that they were partners.

VICE CHAIRPERSON McLAUGHLIN: One more question from Montye?

MS. CONLAN: I was interested, actually intrigued in your creative method of going to the laundromat to contact respondents. And you mentioned that it helped you to learn. I was interested again when you tried to pass that information on, was that accepted for weight to the more scientific studies and the other more formal qualitative studies?

MS. LOWE: I think it was a balancing act.
But I think we listened to one another. And I think the public, every meeting we had was open. And so they could respond if indeed they wanted to challenge some of our anecdotal findings. But I think that other members of the Commission also went to special places to seek information. And some trends call it elevator talk. And I won't tell you the places that I went to get the best information.

VICE CHAIRPERSON McLAUGHLIN: Thank you very much. Thank you.

Now we're going to be hearing from Diane Lovell and Dr. McDonagh. And I understand they've reversed order, and we're going to start with Ms. Lovell who began her career as a union advocate at the age of 21. It doesn't give the year for that, so we're safe.

She has represented a variety of employees including health care workers, correction staff, public defenders and general government employees. Diane is currently a member of the Oregon Public Employees Benefit Board and the Oregon Health and Sciences University Employees Benefits Council.

So we're looking forward to hearing what you have to share with us.

MS. LOVELL: Thank you, Madam Chair, members
of the Commission.

It is my pleasure to be here today and talk about the Health Resources Commission work, but I think more we have not had absolutely the smoothest commission in the history of Oregon. And I'd like to speak to some of those challenges and how we worked through those challenges.

When the Health Resources Commission was initially established it focused on further review of medical technology, medical procedures. And there was a lot of pushback. It was a new commission. There was a lot of resistance from drug manufacturers, but also manufacturers of medical products.

We spent a lot of time developing a very, very public process which worked very, very well. We had a technical advisory panel which consisted of physicians, of other experts and they reviewed all of the medical evidence that a staff to the Resource Commission pulled together. It was a very public process.

And at that juncture the Commission then really added public policy to the scientific evidence. So we would get a report from the staff, we would think about how it would impact on Oregonians and the state
and we would make recommendations. But there was really not a forum for those recommendations.

After a couple of years in the next legislative session there was really an attempt to undermine the Commission's work and they created legislation that would really cancel it. And we languished after that for a couple of years. We weren't abolished, but it was just a very uneasy relationship amongst the state legislature and other policymakers in Oregon.

Former Governor Kitzhaber gave us actually a challenge, which sort of brought us out of semi-retirement. We put together a project looking at mental health drugs and making some recommendations. And we then reinvented our technical advisory panels, brought a nucleus into play. But at that juncture it was even a more open process. And I do want to talk about the sort of the way we incorporated the public. But we made a very significant effort at that point to involve some of the advocate groups, real people because it was beyond public policy. We really needed to hear about how all drugs were -- and how they impacted their lives.

There was a reference made earlier to suits. I swear that within 24 hours of the charge, people from
all over the United States and outside the United States
got on planes and headed to Oregon. You were seeing for
the first time representatives of the drug
manufacturers. And it was a very, very intense process.
And still at this point our staff was gathering --
evidence for the review for the Commission's review. It
was a great process. We had wonderful public testimony.
Wonderful testimony of these groups. And people had
been getting all scared that, you know, we were about
making sure that new drugs weren't utilized in Oregon,
that they were too expensive. And we were able to show
through that public process, a very transparent process,
that that was not what we were about. It really was
about the science that offered compassion and
understanding that we need to look at what's going to be
people productive in Oregon, what is going to improve
their quality of life, it's all those factors which are
in consideration.

After that we were sort of again a
Commission and took a more serious look at drugs and
drug family. And at that point in time we started
working with the Oregon Evidence-Based Practice Center,
you'll hear a lot more about. And that was a really
fluid process.
Again, the process of the Health Resources Commission change. The Commission, again, was tasked, the technical advisory committee. And in these recommendations, but we really did not apply public policy to any degree. It was really about in the first phase the eligible key questions and then we were tasking that to make sure that they had answered those key questions.

The other thing that we were charged with, and this was again a big political issue, was to provide this information to the Oregon Medical Assistance Program. Not to advise them on what drugs people should have access to, but to provide the scientific evidence within drug families which drugs would be fully effective. We gave them pricing information, but what then they made available to patients was up to them. But that was a very gray area. And then people, the Health Resources Commission was making those recommendations, I think sometimes people were led to believe that. And again, just very frankly, representatives of different pharmaceutical companies really made great efforts to muddy that process. And it was very difficult, but at the same time because our process was so bare to the public, whenever
misrepresentations happened, we were always able to go out to this public meeting, this public technical advisory committee, this public motion; there was nothing that didn't happen in the public and there was nothing that didn't happen where there was a very significant electorate. So it was really very valuable.

We, and largely would have a doctor -- his credibility, we've handled hundreds of volunteers and thousands of hours of volunteer time. A very busy time. Physicians, pharmacists, nurse practitioners, a variety of people. And it has been really amazing.

I think that the OMA really understanding that this is a scientifically based that physicians really were providing the technical information was very, very important. But the other thing, the public process. The fact that there are four non-physicians on the Health Resources Commission, too, specifically consumer representatives have been very, very valuable. Because it extends -- this information is very, very technical. Lay people can't understand it. Lay people can explain it. Lay people can advocate for its acceptance. And I think that is very, very unique in our progress. And I would just really urge -- as you look at different models, I would just really urge to really
champion those types of models because they are so very valuable.

I think that as the Commission moves forward, they're now again looking at the medical technologies, which is where they started, in addition to continuing to do the work of reviewing different families. I think that we'll see a lot more positive changes and more recommendations.

Again, I think the Oregon Health Policy with the Health Services Commissions is looking at technology, each of us is beginning to do so. We are sharing information and sharing it with other public bodies such as the Public -- Board. So in Oregon we really are, it's very organic. There is a lot of sharing information and a lot of synergy to handle the different groups. And I think that it's been really a positive experience.

And a positive experience from the perspective of organized labor having a unique opportunity, I guess I would say, to sort of speak into a collective bargaining process, which as you know is very contentious around health care, to sort of speak into -- it makes sense to use evidence in making medical decisions and really having an opportunity to teach
collective bargaining around that philosophy it's been a unique experience for me. And I really appreciated that opportunity.

VICE CHAIRPERSON McLAUGHLIN: Thank you very much.

The fact that you're keeping recommission suggests that you're doing something right. So we appreciate your input.

You suggested that we were going to hear more from the evidence-based, and that is in fact what Dr. McDonagh is going to add. Perhaps we should hear from her, and then if you would be willing to stay, we can ask questions of both of you.

Dr. McDonagh is an Assistant Professor of Medical Informatics and Clinical Epidemiology, a core investigator with the Oregon Evidence-Based Practice Center and a principal investigator of the Drug Effectiveness Review Project.

She has been a Clinical Assistant Professor at the University of Washington School of Pharmacy and Geriatric Medicine Team Clinical Pharmacists and Director of Investigational Drug Services at Harborview Medical Center in Seattle. And so I'm eager to hear more about the evidence-based research and how this
blended in together, and we look forward to your comments.

DR. McDONAGH: Thanks very much for listening to me this morning.

I want to tell you about our link with the Health Resources Commission here in Oregon, because I think it was unique.

I want to go through the methods that we used in our reviews, but what I want to highlight in that is the part that is unique in the Oregon process, the part where it incorporates public comments.

When we were asked to work with the Health Resources Commission we were given some challenges. First we were asked to apply our systematic review methods to comparative questions and in this case comparative drug questions, but with public input which was somewhat unique.

Additionally, in producing these reports we were asked to make sure that our methodology was consistent, across all reviews. Make sure that our methodology was transparent. It was very clear what we had done, why we had done it and how we had done it. To make these reports very readable. We wanted to make sure that the committee members who were using them...
would be able to locate information easily, get to the bottom line, what are the conclusions from this body of evidence.

And also we wanted to be able to ensure that our researchers had the least potential for bias possible. So like you, we also required the highest bar for conflict of interest, which was absolutely none, in order to be a part of the research process.

So, we started the review. Whenever we start a review the very first step is to identify the questions. What is it that you would really like to know from this review. We did this process through multiple meetings with the subcommittees that were developed by the Health Resources Commission. An individual committee for each report was put together with experts from various fields. And so we met with them multiple times to talk about what it is they wanted to know.

In general, our reviews always had three questions. The first question was about comparative effectiveness, looking at the different drugs in that same class, looking at efficacy or effectiveness.

The second question was about tolerance and tolerability. Both the short term adverse events
lead to tolerability differences and also long term harms. In looking at comparative evidence between drugs over many months and years, to see if there are any differences.

And the third question is a very important question, looking at both of those first two questions in subpopulations. So other differences between these drugs in effectiveness or harms when you're looking at subgroups based on age, gender, race or ethnicity, co-morbidities or other medications.

Those were the key questions that we started with. And those were developed in a public process. So we did have input on those key questions from the public at that time. Also they were posted to a public website for additional input.

The next step in the systematic review is to try to find all the literature on this topic, both published and unpublished. And we start with multiple electronic databases such as MEDLINE. We also send out requests to the pharmaceutical companies manufacturing the drugs that are included in this particular review requesting information on any study on their drug, whether that has been published or not. We also then search the references, first of all, of any studies that
we uncovered. And we go back to our committee and ask them as experts if we missed anything. And we also search the FDA documents that are available on the FDA website, which turns out to provide quite a lot of valuable information particularly for the newer drugs.

Now that we have this group of studies identified from searching, we then apply our inclusion criteria. The inclusion criteria come directly from the key questions and they cover four main areas.

The first is the population, including the groups of patients in the review who have an interest in the evidence pertaining to it.

Second is the intervention. In this case we have a specific list of drugs that you want to have included in this review. We would always review different formulations that were available, for example extended release compared to immediate release as different drugs.

We also have included the criteria around outcome measures. For these reviews we always preferred health outcome measures, things that are important to patients, so mortality certainly, morbidity outcomes such as heart attack or hospitalization. But we generally did not include intermediate outcomes such as lab values and
blood pressure changes, for instance, without those other health outcomes.

And the last area where we have our inclusion criteria is the study design. For effectiveness we generally include randomized control trials. But when we went to look at harms, we also added observational designs to try to evaluate the longer time harms in a broader population.

So once we have identified the final list of studies that were going to be included, we then quality assess each individual study. And we give it a rating of good, fair or poor. And the first quality study because we believe that they have a significant risk of bias, were not included in our trial since it was reflect in the evidence.

We have also designed a quality assessment of over all body that is for each individual key question at the end of the report.

The next step is to take all of these studies that we've identified and extract data from them, put them into tables so that readers can look across the study and evaluate the same data from each study and try to get a comparison in a head-to-head fashion.
We also then go about doing our analysis. Generally that involves a narrative synthesis and where possible we will do quantitative analysis doing meta analysis or other techniques.

We have found that when you're dealing with within-class reviews, it turns out that meta-analysis is not possible as often as it is with cross-class comparisons. And so our reviews have some meta analysis but it is not appropriate for all of the reviews.

Finally, we produce the report. Anyway, this is the most important part, again, trying to focus the report - have them be transparent, direct. And every report has a summary table that is a summary of the evidence by key question. And these reports undergo peer review. The Oregon Health Resources Commissions subcommittees review them and then they also go out for national peer review.

Importantly, they are posted for public comment. And in addition they are presented in person at a subcommittee meeting were it's also public. And we have had quite a lot of public comment on our reports through the 3 years that we've been doing them. And we really find that approximately 80 percent of the comments that we receive do come from within the
pharmaceutical industry. We do get some comments from advocacy groups and very few from individual private citizens.

Looking back over all the comments we've had we would guess that approximately a third of the comments are substantive. Many are really about other issues or taking a stand on the decision-making process, which is not part of the evidence, but really are about issues we didn't review. In approximately a third of those we have actually changed the reviews because of them. So we have found that the public process has been quite useful in improving the quality of the reviews. But that's been very important.

We also send our reviews to the Agency for Health Care Research and Quality whom we ask to review them for methodologic quality so they give us their stamp of approval for methodology.

Each review then undergoes an update either every six months or every year. And the timing on that is determined by the Subcommittee. We give input to the subcommittee based on what we see happening in the literature, but it is really up to the committee to determine how often they want to have it updated.

When an update begins the process is that
the key questions are revisited because things change in medicine. And it may be that in using the review in their decision-making processes that your key question was off target or maybe that something new has happened in the year that you did the review, and -- the optimum measure of -- in the last year. A great example of this is in the statins review where new evidence has come to light and HDL has become more important and so that outcome measure would be added to the review.

In addition, new drugs are continually being added to some of these classes so that is another reason for reviewing the key questions. After that the process continues as usual and we end up with our update review.

And again, the final reports are posted on a public website. The key questions and draft reports are posted for public comment. And then the final reports are posted for use by anyone.

That basically summarizes our methods. I'd be happy to take any questions.

VICE CHAIRPERSON McLAUGHLIN: Thank you. I had one question. And that is with drugs in particular there are different side effects for different drugs. And you talk about outcomes. Do you incorporate that? And I ask because consumer preferences, of course, vary
according to their tolerance for different side effects and what they're willing to give and take. Do you incorporate that in what you do or is that in a different part of the process?

DR. McDONAGH: I think that it's both. I would say that from our point of view is how we produced the review we try to present balance of benefits to harms for each question, although a lot of times we find that for long term harms there's evidence about individual drugs but it is not comparative. So we feel that sometimes giving -- really has a lot of doubts but we give them what we have -- is actually more a committee decision.

MS. LOVELL: And I would say that we have a very strong interest publicly on what is effective but always the key question is -- what are potential harms. And I think that is one of the benefits of the program as new drugs come on the market so very rapidly, very often we don't know what the negative side effects can be -- should be mindful of that.

VICE CHAIRPERSON McLAUGHLIN: We're going to take one question from Chris and then --

PARTICIPANT: I have a question, too.

VICE CHAIRPERSON McLAUGHLIN: Are you going
to go get us lunch.

    Go ahead, Chris.

MR. WRIGHT: I have a question in regard to new drugs coming on the market, particularly as it relates to research and the pharmaceutical or drug research that we have. And did that play into your program or they were not looked at? That was outside of your scope?

DR. McDONAGH: We thought that if a new drug come out that was within a class that was reviewed, then it certainly did have a big impact. We would review that. If it was completed, it would be done in the next update.

    But typically if a new drug is coming out the committee would decide to have the update sooner. So we would pretty much finish the report and start the next one.

MR. WRIGHT: So you were just looking at FDA approved drugs. You were not looking at protocols at all?

DR. McDONAGH: That's right. We would be keeping an eye on what we knew was coming in order to inform the committee, but we did not review the evidence.
MS. LOVELL: I think maybe both of us neglected to mention is we only utilized public study. So if the public couldn't look at the study, that they were not considered. And so that really forced us to look --

VICE CHAIRPERSON McLAUGHLIN: Did you have a question?

MS. MARYLAND: My question is the relevance in terms of how you took that information and create a formulary I'm assuming for the health care plan? Because I'm trying to get the link in terms of the relevance, in terms of how you used that information to be able to reduce costs possibly for pharmaceuticals.

MS. LOVELL: And that gets back to that gray area. Because there really is a handoff. The Health Resources Commission could use the finance and the recommendation in terms of within this -- these five are all basically equally effective. And then the health plan determined which of those drugs that they're going to pay for.

VICE CHAIRPERSON McLAUGHLIN: Frank will have the last word.

DR. BAUMEISTER: Well, this is my playground for a decade, and I know a little bit about it. And I
don't think I see any drug salesmen here today and that's unlike our meetings when we hardly can find seating for the public because the drug salesmen were there and they flew there from all points from all over the land to really assail and assault this program. Because this program is really expensive.

And I think it should be pointed out to my working group here who are sort of awestruck by hearing all this stuff, and that's why they're quiet. They're not that hung over.

The costs for pharmaceuticals for the Oregon Health Plan exceeded the cost of physician hospital costs altogether. We're talking about big money. You know, a million dollars here, a million dollars there. So we're talking about big money.

And, for example, when they reviewed the literature on the proton pump inhibitors they reviewed, I think, 3,000 articles and found that approximately 100 were worth the paper they were printed out. The rest were not signouts. It was advertisements, propaganda and physicians read that trash and the public reads that trash. They see the purple pill on television. And you need objectivity somewhere in there to make some sense of this business.
The Medicare drug plan that Senator Wyden says he has the welts on his back from was in some ways a give away probably to the insurance companies and to the drug companies. And I think that this program here, which is unique as you said the way it was put together, the way it was constructed it had to be good because it aroused so much ire in the pharmaceutical business. We never had such -- the airports were busy here bringing -- we had 25 lobbyists in the Capitol at one day and I think I was the only defendant of the program. And it's where then Governor Kitzhaber drew the line in the sand for Senate Bill 819 that created the Practitioner Management Drug Program over create opposition from all those lobbyists.

And the question I have is I know that Dr. Kitzhaber, in addition to Estes Park obligations is still involved with this evidenced-based pharmaceutical program that they've taken out into the nation, and I think there's something like 15 states or organizations that have signed onto this program, which would perfectly align itself with our program.

Somewhat pessimistically, the fact that there aren't drug salesmen and representatives from the Health Industry Manufacturing Association in this room...
points out that there are people out there that don't take this working group seriously. Because if they did, they'd be lined up right outside right now.

VICE CHAIRPERSON McLAUGHLIN: Thank you very much for your contribution.

We're here in the last stretch before lunch. That's always an interesting position to be in to be the speaker between the group getting to lunch.

We're going to reverse this order, too, I'm told and start with Dr. Goldberg who is administrator of the Office of Oregon Health Policy and Research. Dr. Goldberg is a family physician and has devoted his entire professional career to public health policy and to improving the organization and delivery of health services to vulnerable populations.

He received his MD from the Mount Sinai School of Medicine, New York City. Did his residency at Duke University. You went then to New Mexico and then finally, I guess, as one of these pioneers immigrated to Oregon.

DR. GOLDBERG: And you know I'm from New York.

VICE CHAIRPERSON McLAUGHLIN: I know.

DR. GOLDBERG: And worse than that, I
thought I was in a bad position because I was standing between you and lunch. But now I also am following Frank. And so following Frank and you getting to lunch puts me in a tough spot.

So I will forsake eloquence for brevity. John Santa, I am competent and I know can be both brief and eloquent, but I'm not quite as talented.

You've been here today and you've heard a lot all morning long. And the purpose was for you to hear one chapter of the Oregon story. You know, this is a process in evolution, but the rest and hopefully the best is yet to be written.

And John's and my job this morning is to sum it up for you. And I'm going to try to sum it up for you with seven lessons learned, many of which you've heard today, which will allow me to brief. And John is going to follow with some principles upon which we can move forward. Because as we've done this and as we've innovated, we've evaluated what we've done. And that learning has really helped us continue, and it really fuels us towards our goal of continuing to improve health care for people in our state.

So lesson number one, and since I am a New Yorker and it is baseball season and the Yankees are now
in first place, you've got to believe. You really have
to believe that you can make a difference and that your
work is important.

You know what we learned here that the
ingredients of: (1) valiant; (2) public process; (3)
hard work; (4) leadership, and; (5) political muscle can
really be harnessed to help improve the health of the
state. Our attempt at doing that was what you've heard
today, the Oregon Health Plan. And, indeed, it was
successful. You know, we improved the health of
individuals in our state, we've seen uninsurance
decrease dramatically at the height of the Oregon Health
Plan. We saw uninsurance in kids go from 21 percent
down to 8 percent. In our hospitals drop by 50
percents. The numbers of emergency room visit dropped,
the numbers of low birth weight children dropped. Low
income individuals in our state had dramatic increases
in preventive care to keep them healthy. And, you know,
this increased accessed to health care for our citizens
decreased cost share to our business, it helped us
create healthier communities, healthier health care
systems and better live for the people in our state.

Lessons number two, and one of the ways we
got there and you heard this morning was explicit
allocation of resources is not only necessary, but I think we showed that it works. That the reality of fiscal limits makes choices about resource allocation inevitable. And through our use of the prioritized list, which you heard this morning, we were able to allocate resources in the way that made the most sense for people in our state.

That brings us to the next point, which is the next lesson, probably the most germane to you which is that public process is essential to that, and it was essential for our success and you've committed yourselves to that process. And I'm not going to repeat more that was said, because I thought that Mike Garland and Ralph Crawshaw said it most eloquently. But what I'd like to do is give you an example of how you can sort of harness that. And that's this: You know, if you believe that you can sort of ask people what they want, so go out, have a problem process and ask them what they want and then operationalize it, we prioritized it and we then operationalized that, it can work. But I'm going to just for a moment take our experience here in Oregon, what we've done and I'll leave you with a five page analyses.

We've taken our prioritized list and where
are line of services is now drawn and we have very successful in delivery and whole package of health care services to individuals. Take that line and extrapolate that to the entire nation. And what you'll find is that you'll save about $5 billion a year in health care costs. $50 billion in ten years and then go one step further. The objective isn't just to save money, it's to help make people healthier. And that's what we do.

So take that money and rather than cutting Medicaid for a nation, you could add over 2 million people to the Medicaid rolls in our country, 2 million adults, you could cover over 5 million children for that money. So you can make this work. Public process is essential.

Also, as you heard from Frank and from others, and it's the fourth lesson: Evidence is essential. Regardless of what we do, regardless of whatever health care system we choose to adopt, we're going to continue to face an unsustainable system unless we can reduce the rate of natural inflation and unless we can do what we all need to do, which is pay for things that work and that improve people's lives and don't pay for that people that don't. Evidence is the key to that.
Lesson number five, somewhat of a political lesson. Community delivery systems work. Tip O'Neill said "All politics is local." In many ways all health care is local, and as you heard this morning when you go into the communities you'll hear that communities have very different issues. But there is a common theme that we've learned. And what we've learned is that communities have been most successful when there's an environment in which community-based clinicians, hospitals, ancillary service providers and community members come together to help meet their local needs. Communities that share equitably among the providers the responsibility of creating healthy communities have really been the most successful. And you've heard this morning about some of the community-based health plans that we've created in this state which really have been very successful in operationalizing this vision and in taking it to communities and making it work at the local level.

Our sixth lesson, essentially our most recent lesson is that cost sharing or cost shifting to the poorest individuals limits their access to their care.

You know, we founded the Oregon Health Plan
on a principle of eliminating cost share. And we believe and continue to believe that shifting, concealing, minimizing the true cost of care, you know, really undermines effective public policy. And with that said a few years ago we increased premiums and copays in the Oregon Health Plan for our Medicaid population for our most vulnerable citizens. It was a noble goal, the idea was to increase the premiums and copays and using those savings to actually cover more people. In essence, what we tried to do with our prioritized list. And our experience now really well documented and well evaluated shows that, you know, these policies have had a number of unintended consequences and they've led to many of our most vulnerable citizens losing coverage and going without necessary health care. So that was an important lesson for us.

And let me leave you with the seventh and last lesson, it really is perhaps the lesson that Governor Kitzhaber left you with. It's that no plan is an island and that the Oregon Health Plan is part of a larger delivery system.

Many of the challenges that the Oregon Health Plan faces are not unique to it as a public
health program. And I think that it's critical to note that the Oregon Health Plan exists as part of a larger health care system. And as you all know all too well, it's complex, fragmented, costly. Health care costs nationally are soaring. Individuals can't afford health care, business can't afford health care. Our rates of uninsurance are increasing. But you know, in fact, the increasing number of uninsured Oregonians since 2001 is largely attributable to the decreasing enrollment in employer sponsored health care and not to the cutbacks, although we've made cutbacks, in the Oregon health plan. That's because of the economic circumstances that existed.

And you know exacerbating the economic challenge is the private and public sector face is the fact that our health care system lacks incentives for promoting access to effective medical care and cost containment or quality.

And so in short because the public and private sector both utilize the same delivery system, they're inextricably linked. And in the long run both sectors ability to maximize the value of what they do to the value of their being able to improve health is really the key.
You know, on its own the Medicaid program you know is neither a problem or a solution. It's part of a larger health care system. And that's indeed how the Oregon Health Plan was originally envisioned. And with that said, and in the efforts of brevity, let me turn things over to John Santa.

VICE CHAIRPERSON McLAUGHLIN: Thank you very much.

Next we're going to hear from Dr. Santa, who is the Assistant Director for Health Projects of the Center for Evidence-Based Policy at Oregon Health and Science University. He was previously the Administrator of the Office of Oregon Health Policy and Research. He has been involved with issues related to the uninsured, Medicaid, prescription drugs and evidence based medicine. And we're counting on you to sort of wrap this all up.

DR. SANTA: And I'm going to do that, and really briefly.

You all have actually my written comments in your packets. There are copies over there for the public. And I'm going to be very brief.

First of all, I want to say thanks for doing this. I just really love people who are willing to do
this, like the folks who have come before you today.

Thanks for coming to Oregon. We really appreciate you coming and listening to what we have to say.

I know you must be looking at your task and wondering if we are developing a health care approach similar to Woody Allen's world view here. Woody said "More than any other time in history mankind faces a crossroads. One path leads to despair and utter hopelessness, the other to total extinction. Let us pray we have the wisdom to choose correctly." We don't feel like that. We're not at that crossroads, and I hope you come away feeling there's a lot of optimism that this is tough stuff, but we can get it done.

I'd remind you of the goal. When I went to work for the state of Oregon, John Kitzhaber brought me into his office. In the room, he looked me right in the eye and said "The goal is health. It is not health services. I don't care about health care. I care about health."

And here are the rules. You have got to improve equity. You have got to figure out value, that's what we learned in our prescription drug project. This has got to be transparent. You've got an advantage
when you make it public because the other folks are not used to working on that playing field. You have got to be explicit. Don't be afraid to tell people exactly what you're doing. And we have all got to feel like we are in charge, so you've got to give away some local control. It's the middle of our health care system that we don't have any about-- we don't have those hospital boards, those care groups. You know, this is an industry.

I'll end, really, with what I think is a very sweet paper and a comment from this paper by -- I've probably breached some copyright rules by putting it in your packet.

Marthe Gold went to England to study priorities. And the English are at the same point we are -- looking at their health care system. And she basically listened into public sessions including, including teas that she would go to where really, as you'll see if you have chance to read the paper, they talk about these same kind of issues. She closes with this statement: "Our next great wave of empowerment will come when we begin to think at the population level by asking the public for its views on the health care system: What should our country provide and how should
it be paid for? These are no less life and death decisions than those made at the bedside." Interesting, she's got the population and individuals included. "Listening to public voices could help us move our stalled efforts of health care reform forward in a publicly responsive and responsible way. Maybe we'll even adopt the tradition of afternoon tea. Worse things could happen."

Thanks.

VICE CHAIRPERSON McLAUGHLIN: Thank you very much.

(Applause).

VICE CHAIRPERSON McLAUGHLIN: I don't know whether anybody had any questions for Dr. Goldberg or Santa or whether you would be around for us to talk to over lunch maybe.

We were supposed to reconvene at 1:00.

(Whereupon, the working group was recessed to reconvene at 1:00 p.m.)

[transcription resumed with hearing in process]
A-F-T-E-R-N-O-O-N  S-E-S-S-I-O-N

1:30 p.m.

Dr. GANZ: . . . in 1992 I worked for them.

And the basic idea was that people as a community would pool their resources and that it wasn't about themselves, it was about pooling their resources to help someone in the community in a time of need. And only secondarily was there a notion that maybe they get sick or they might get injured and that community would be there for them. That was the principle upon which this was founded. And I would submit that this is still a fundamental principle that is at work and can be at work today.

I hope to believe, however, that we have gotten far away from that principle. In the public discourse, in the way that we view the system and, frankly, the way that the system functions it does not function out of that fundamental good place; people being there for one another. Instead, it's been replaced with a system that looks more like an entitlement system in which everything happens behind the platform and the focus is amongst the players in the system, if you will, institution to institution. And
the individual patient is kind of a icon in the entire affair. Think of it as when health insurers are negotiating with hospitals and hospitals are talking with physicians and insurers are talking with physicians and people are talking to pharmaceutical companies. It's like titans, you know, stomping around the meadow looking at each other and the individual consumers are the ground. That's my sense of much of what we have in the system today from the perspective of a consumer.

I come by this somewhat honestly, I guess, in the sense that my dad was a physician in Spokane. He was a family doctor. And he was a Marcus Welby physician, if you will, if you remember that show. He delivered babies, he did minor surgeries, he did house calls and gave away a lot of care free to various religious communities. He was Catholic and so many of the religious communities in Spokane got free care from my dad.

And he always -- well, he did many things and he took great pleasure. The thing that he took the greatest pleasure in was the ability to diagnose that very difficult disease. And he credited his own success in that was because he took the time to get to know his patients. And he did that at considerable cost to
himself because that was not the way that the third party payment system was structured to work. But he thought it was important.

However, about three years ago, maybe it was actually about four years ago, we started noticing some changes in our dad. He had retired. And we just started noticed as his kids that he wasn't quite the same person we had seen before physically.

It started with a very bad backache that he had. And he went in to see his doctor, and the doctor spent about five minutes with him. Looked him over and said I think you've got early -- I think you've just strained your back. Sent him away with some medication.

Three months later it wasn't getting better. We came in, did some tests. I think he did an x-ray or an echo or CT, determined that they found that he had early osteoporosis. Sent him away.

A few months later he started having issues with his eyes. He wasn't seeing very clearly and that this was coming up very soon. He was sent in -- or he went in, went to the doctor, he was referred to an eye doctor. They did a bunch of tests looking at his eyes, determined that -- I forgot what the condition was, and they started treating it with some new medication.
A few months later he came back into the hospital because -- or came back to the doctor because his mind wasn't working very well. We were noticing he was getting very foggy. And so they looked at that and decided it was an early Alzheimer's.

Then he had a compression fracture if his back. And he went and they looked at it and said, no, this looks like osteoporosis getting worse. Treating of this either adjusted his dose of medicine and sent him away again.

Eventually he was so weak he could hardly stand. And it was only then that his doctor actually took time to weave together the various strands and the insight came that maybe this wasn't just a bunch of individual symptoms, but it was something there. And they diagnosed that it was multiple myeloma. And at that point they had him by the throat. And while he did, you know, go to the hospital and get stabilized for a time, it was a little bit late.

I told you that story not because accusing anybody of doing anything bad. But it's a little indication the way that health care works. I think you probably have stories in your own family that are not dissimilar. The system that creates incentives to move
people through the system, to not necessarily spend
time, to not create relationship but to treat particular
conditions in an episodic way and throw technology at
it.

The other experience he had was when he was
in the hospital, what was particularly interesting for
all of us as a family was, watching how he was treated
in the hospital. He was treated in the hospital that he
had done most of his work, and he was well liked at that
hospital. And yet when he was there the most basic
human needs were hard to come by in the hospital.

When he was in intensive care he got all the
technology that he needed just to keep him alive. But
when he was on the medical floor he was made to wait on
average 45, sometimes even 60 minutes to just get help
to go to the bathroom.

And we kind of looked at that, and because
he could afford it, he was able to -- my parents were
able to get a 24 hour duty nurse to privately come and
sit in the hospital room so that when he needed to go to
the bathroom or needed basic needs, he had that.

Now, what is the lesson there? What is it
saying to us? I don't think it's saying that they were
bad people. I don't think that they were saying that
there was an evil intent. I think what we were seeing was a system that's been set up to operate in a particular manner with business processes that operate in a particular manner. And the investment follows the money. So from a hospital perspective, they make investments related to the many referring physicians who want a particular type of technology to be able to serve their patients. And the hospitals want to keep physicians within their hospital not going to work to somebody else's hospital. So investments are made to try to make sure that there is the right technology. But the attention is not necessarily on the patient. It's on the referring physician, to use that exactly.

But I think it's repeated throughout that when you have a system there there is not an economic relationship between the patient and their physician or the hospital. That you shouldn't expect that necessarily the hospital or the physician, or whatever is going to give it the same attention as if there were an economic relationship.

It's made worse by the fact that prices are hard to come by. If you want to take control of your own health care and you want to go to a hospital and you want to find out things cost, it's very difficult to be
able to find out.

When we are second day here in Portland, we went to the hospital for a tour. And we saw this beautiful maternity ward. Very impressive. And they talked about all the low lights and the stereos and the nice TV and that. So I asked what this would cost for a noncomplicated maternity. And I asked five different people, including people in the billing department who could not help.

Now how am I going to be a shopper? How am I going to know when I can't get that kind of basic information?

So I believe that we have an opportunity here now to reset. We have to opportunity because there is such a sense of crises in health care that often when there is that sense of crises like we're seeing in the Gulf region in a different context, that we also have a tremendous opportunity for creativity to create a better world. And our company is focused on that.

So here's, I guess, what I would say is that we have a problem with access and we need to address that. But if all we do is change the payment relationship or come up with a novel way to address access to get more people under the tent and we don't
create a better tent, the tent will still collapse. That merely, and frankly, by trying to put more people underneath it, it will collapse faster than it already is now. And that the challenge that you have, the challenge that we all have is to get at the economic rules that drive this system and change those at the same time we're trying to address access. That is where I think the long term win is, the long term gain is. And let me talk a little bit about that.

First off, I think we have to stop the blame game. Right now I think very much of the system is people are so upset that they're looking at who is at fault. Well, I'm here to say on the record today that we're at fault, our company. We've been part of the problem.

And about two years ago when I came into this role, we took ourselves through a very difficult and introspective process of looking at how we operated within the system and how we helped perpetuate brokenness, tyranny and fear in the system. And what was interesting was is it wasn't the people. You know, we've had a few people within our company that, frankly, enjoyed power and exercised it at the expense of others. But really what we found and where the evil lay within
the company, if you will, was in our processes. The fact that we had clearly focused for many years as a wholesale institution; we sold to businesses. And so we built our infrastructure and our business processes to serve brokers and to serve businesses. And we did not focus so much on the individual member.

We had good transactional capability; payment of the claims, you know answering the phone. And we measured. But what we measured was more in the nature of how fast, how many and not necessarily was there a customer satisfied at the other end. The reason? That was because we were serving a business and what the business wanted to see was how fast and how many and how efficient in that respect.

You can look at that across hospitals, across doctor's clinics, across pharmaceutical companies, you name it in health care, this system is built today on an institutional wholesale proposition because that's the way the money flows. And what we're working on as a company, and what I firmly believe, is that the answer is to move back to a very clear focus on the consumer, the patient and build our processes around that.

I know in an earlier hearing you talk about
electronic health records and you had some information on informatics and clients. I think it would be a terrible mistake if we embraced that technology and use it as an institutional proposition only so that we can continue to play big brother with regard to that information as opposed to building and using the information to give consumer better tools and better information to open up what is now an opaque system to bring light there for individual consumers.

One of our key initiatives for next year is to work to build out a personalized health care record, one that the patient owns, not one that is owned by the hospital or governed by a physician. But one that becomes portable and can be highly accessible so that if a patient is in Florida and is in a car accident there, who lives here in Oregon, they can have access or their doctor there can have access to the basic information that will hopefully make sure that they're only treating the conditions that were caused in the accidents and not create a new problem, for instance giving a drug that they're allergic to or something else because they simply don't have access to that information. That there's opportunity, and that's just a little example. But the idea being that we build it around the consumer.
I this year moved to a HSA product because I wanted to see for myself what it was like to operate without insurance, if you will. Because for the first $3,000 of any payment that our family needs this year, that's coming right out of our pocket now. And it's been a fascinating proposition and I've learned a lot. It has confirmed a lot of what I believe.

When I have gone to the doctor I have found that it is very difficult to find out when things cost. And when a doctor wants to order a test, I've challenged them. Well, why do I need the test? Is there anything in my history that really suggests I need this test.

And in my recent encounter the doctor, after some back and forth, he said "You know what? I don't think this is really necessary." But had I not had the incentive to ask those questions.

Oh, by the way, when I asked him how much the test would cost, he didn't know. And when he asked his front office person, she didn't know. So we just made an assumption of how much it would cost and then talked about whether or not there was value in having the test. And we decided that there wasn't.

I think the opportunity is to have those
kinds of conversations, to accept those kinds of conversations where in fact the patient and the physician, the patient and the hospital are in direct economic relationship. And through that will come the economic discipline that you see in other areas of health care that aren't subject to a third party payment system.

For example, lasik eye surgery. Compare lasik eye surgery, if you will, with cataract surgery over the last ten years. There's not a whole lot of new exciting stuff going on in cataract surgery. One thing that is true is that because techniques are better, they're able to do more units in the same period of time than they used to.

If you look at the cost to the system of cataract eye surgery over the last ten years, you will see a marked rise that is not that dissimilar to the general inflation rate in health care, which unsustainable, we all agree.

Compare that with lasiks. Over the past ten years what's happened in lasik. There are more people doing it. The technology has gotten better. The results, outcomes are generally better. And prices are falling pretty significantly over the last ten years.
The difference? One is exposed to a market and has the economic disciplines where patients are shoppers and have tools and can get information on pricing and get information on different providers and the other is not. That's just one of many. If you look to alternative health care provider and see the same thing. That prices tend to maintain reasonable levels, efficiency get better. Oh, and by the way, customer satisfaction is very high because people rather than operating in entitled fashion are actually operating in a market fashion. And the response and the focus of the provider community, in that respect, is on the patient because that's who is paying the bill.

What we're doing as a company is moving in that direction. We have said that our fundamental business proposition going forward, the value that we have, is to individuals and it's not been between the individual and their provider. It's to facilitate that relationship. To provide tools and information to help people and members of their family who navigating care. And we believe that the lessons of history will tell us that in fact we can over time increase the satisfaction of individual patients by establishing a relationship and at the same time bring more fiscal and economic
discipline into the individual relationship, into the point of service.

In the near term we'll probably continue to sell primarily to large employers or small employers or state entities. But our hope is that those entities will also see that the primary value proposition for the long term is focusing on the individual member and helping them become better, more disciplined shoppers of their health care. And that the overall system, as it does it any other market-based system, will respond to that and we will create a more consumer focused system and one that better controls its costs.

If we do not that, then I believe that merely throwing more public money at it or changing who the payer is, or you in a sense pandering to an entitlement mentality, we will never have enough financial resources. And given the movement of the baby boomers into retirement years, we will be in for a perfect storm.

So I'll stop there and take any questions.

VICE CHAIRPERSON McLAUGHLIN: Thank you very much.

I do have a question of, you know, this balance between having it patient centered, consumer
centered, the consumer responding to incentives that you articulated and at the other end a more paternalistic setup where it may be the government, it may be actually the physician that your father used to be taking care of the patient and getting to know the patient and really being to diagnose the patient. Sort of how that balance is. And I say that because we do have a lot of research that indicates from the RAND Health Insurance Experiment, which is the only one we really have on a large enough scale from in a randomized control scale to really understand how people respond to financial incentives, such as you mentioned, that particular for the low income participants in that study when they were faced with a HSA kind of high deductible they made choices that didn't reflect what your father would have recommended. They were not able to discern between what was effective medical care and what was elective.

DR. GANZ: Right. Yes.

VICE CHAIRPERSON McLAUGHLIN: And, in fact, the study that is most often cited involved parents who had children, that they were just as likely not to take an infant suffering from severe dehydration due to diarrhea to the emergency room as an infant who just had a bug bite or some sniffles.
So how do you when you're thinking about this from your perspective, what is your recommendation of how do you adjust for that in your situation where you're wanting to have more financial responsibility and the fact of the matter is not everyone is going to be able to engage in the conversation you were able to engage in with your physician in terms of running that particular test? Where is that line drawn and what potential role is there for the physician?

DR. GANZ: Okay. Good question and one that we've given a thought of, and I'm not going to presume here to tell you I have the answer.

VICE CHAIRPERSON McLAUGHLIN: Why not?

DR. GANZ: You know my sense is, and maybe I didn't say this before, but I think the first thing that we have to do here is we have to establish true north. We have to know what direction we want to take. In a sense, what kind of health care system do we want for our kids and our grandkids and how do we want that to look? Because right now we haven't gone through that work as a nation. And because of that, I think different people have different visions. And therefore, the activity is not necessarily all moving in a common direction. And I think part of that is simply because
we haven't taken the time to sort of -- there hasn't been enough maybe humility in the process for people to say, first, you know there is a problem here and I'm part of it, whatever part I may be within the system. And I've an contributor to that. And why do I do what I do and why am I driven to that and how much I change. And then really look at developing a common vision about where we need to go.

So that's not a direct answer to your question, but I'm just saying that that is -- I think within our own company we've done that and it's moved us in a direction. Why I'm here is to help advocate for I think a much broader progress because I know that the answer doesn't lie within us alone. It's far bigger than just us, and it's far bigger than just Oregon, Idaho, Utah and Washington.

But let me go philosophically at your question. I think one of the big issues is I'm probably a little more education about health care than others, because I work in the system. The one thing I've learned is that I'm also a babe in the woods in terms of having a level of sophisticated knowledge that would help me make good decisions.

First, I would say I have a lot of trust in
the average consumer to learn what they need to learn in
a system where it's demanded that they learn it. That
generally we as Americans when we have needed to learn
something in order to be able to operate within an
economic system, we find a way to learn what we need to
know. And it doesn't guarantee that we're going to
always make good decisions. But I would submit that
under the very paternalistic system that we have today
there are a number of bad decisions being made, whether
they're made by the patient or whether they're made by
the person who is acting in a paternalistic fashion
toward that patient. And that that will never be rooted
out of the system. But I would rather cast my lot on
the individual to make choices and free in making those
choices rather than have somebody else who presumes to
have greater knowledge telling them what they can and
cannot do.

What I do think in a system, for instance as
our company, what we need to do is not be cast in the
role that we have been in the past, which is what I
would call "traffic cop," administrator. That our best
way of functioning is as facilitator. In other words,
get information into their hands and be very skilled
about it. And that's an entirely different competency
than what we've built up over the years.

I mean, our customer service department, whether than merely being kind of a yes or no, yes you can do this/no you're going to do this, needs to have a level of competency that can actually help guide people through a decision making process and give them information so that they can make better decisions.

So the RAND study, I think, probably reflects more about what is wrong today as opposed to what may be possible tomorrow. Because I don't believe that health care is so different than anything else that we purchase or anything else that we interact with in our economy that it needs its own completely different set of rules. I think the reason it operates the way it does is merely almost an accident of history. That needs to change.

And the real key is how do you bring people who have been subject to a paternalistic system to a different value. And I think a lot of that is helping reeducate people as to their role in that and giving them the tools to be able to be as good as decisions as they are. I'm not suggesting that it's going to be easy. I'm just saying that that is the general path we need to take.
Was I responsive?

VICE CHAIRPERSON McLAUGHLIN: I mean you were. I mean, we could engage in this conversation all afternoon, I suspect.

DR. GANZ: Yes.

VICE CHAIRPERSON McLAUGHLIN: But I want other people to ask you some questions.

Pat?

MS. MARYLAND: What are your thoughts about pay for performance, you know, in terms of providers that provide care and that quality is there?

Patricia Maryland. My question is what are your thoughts about pay for performance, relating quality, if you will, now comes to reimbursement.

DR. GANZ: Well, first off, there's a concept of pay for performance. I've always been -- I believe a market works when people get paid for their performance. And then if they don't perform, people vote with their fee to go somewhere else. I mean, that is a market at work.

I'm somewhat suspicious of pay for performance if it's a situation of institutional leverage where one institution says I'll pay you if you perform to my standards, not to consumer standards, my
standard or I won't pay you or I'll pay you less if you
don't perform to my standard. I think that just leads
to the continuing argument, if you will, between doctors
and insurers or doctors and their own licensing
qualities. And it will be a field day for the lawyers,
you know, because of the lawsuits it'll generate. But
I'm not sure that the consumer is going to be better off
at the end.

Again, the concern I have with it is if it's
not consumer focused, then it's just warmed over same-old-same-o.

So as a near term measure I think pay for
performance may be one of those pieces of a bridge that
we might to say, yes, let's do that. Let's try it if it
has some validity or helping us get to the ultimate, you
know get on the path toward true north. But as a long
term proposition, if it's the sort of institutional kind
of pay for performance conversation, I think it has a
short lived usefulness.

If it spurs the notion of sense of the
patients paying for performance in the long term or
patients and insurers together in some partnership
fashion, then yes. Maybe it adds a longer term
significance. Because ultimately you should get paid
for your performance.

VICE CHAIRPERSON McLAUGHLIN: Montye?

MS. CONLAN: I guess I'm interested in your thoughts for a person like myself. I have multiple sclerosis, very expensive to treat, complicated sometimes in the treatment. And so to a certain extent I play the role of lesser in society, if you will.

The point of what I'm saying is my options are a lot fewer than yours. So you can educate me and, you know, put me in the role of empower me but I still have very few options.

DR. GANZ: First off, at the personal level, I obviously I don't walk in your shoes because I don't have multiple sclerosis. And I can only imagine because I do have friends of our family that have gone down the same path you have. I know something, but obviously to not have been there, not have it happen inside my own body, I can't. So I'll start from that premise. Fair enough?

I would submit that individuals in this country who suffer from long term chronic illnesses are served by the same system, the same broken system that everyone else is served by. And that the notion is the need to -- what I'm arguing is is that the system
doesn't function sufficiently and that it drives cost beyond what is appropriate or in your illness as well. And that what we're trying to look at, or at least at drives my philosophy is, without pulling a particular kind of view or looking at any particular -- like how does the system function. And if it doesn't function well, then those with chronic illnesses are going to be pushed out of the system probably faster than the rest because they will not be able to afford the care they need because they need more of it.

So tome when I talk with members of our company, employees of our company who are dealing with chronic illnesses, that only heightens my resolve and belief that we need to get at this current Commission. And that merely trying to figure out how to put more money toward funding care of chronic disease isn't enough. We've got to fundamentally change what drives that cost that causes it to be so expensive in the first place.

Does that make sense?

So, you know, I don't know if I'm being responsive to what your particular concern is, but I wasn't suggesting in my comments that -- I guess what I was trying to get at is is that the system isn't
sufficient. And if it drives costs and it pushes people out and makes it unaffordable over time for people, it's only going to be that more for people that are your shoes, and that we'd better get at it.

MS. CONLAN: Well, I guess the reality for someone like me is that of course related to public health because private insurers don't want to touch me. I have a preexisting condition. A lot of doctors don't accept Medicaid, which I'm a Medicaid beneficiary. So that's what I mean by fewer options.

DR. GANZ: Yes.

MS. CONLAN: You know this market kind of economy that you're describing, I just don't have the same kind of experience. And I think there are many others like me.

DR. GANZ: Yes.

MS. CONLAN: It's not just about MS.

DR. GANZ: Yes, I would agree. And I would say that you described to a great extent what's wrong with the system and why it must change. That's my point. Because I'm not suggesting -- I don't think the system functions in the market today. I've been using a couple of examples of where it can function in the market effectively. But my point was it doesn't
function at a level of market today, it doesn't have those dynamics. So it pushes you into a public funded, it cuts off choices because it becomes almost an implicit ration because of the way the economic rules are set up; that's what I think needs to change.

VICE CHAIRPERSON McLAUGHLIN: Well, actually I thank you for reminding us what we started off the morning with with Governor Kitzhaber that we always have to think about the counter factual. We have to think about well what's the alternative? What else is happen if we don't go this way? So those are some of the tough choices that we're going to have to make in this next year as we talk to the American public of not everybody's going to get everything and you have to say well it could be even worse, which is partly what you're saying. If we keep going the way we're going, it'll be even worse.

So thank you for reminding us of that cheerful note. No. But it is something that we need to keep in mind, so I thank you very much for your comments.

DR. GANZ: Okay.

VICE CHAIRPERSON McLAUGHLIN: Next we're going to be hearing from another person --
DR. BAUMEISTER: I have a question.

VICE CHAIRPERSON McLAUGHLIN: Ops, sorry.

Can it be quick?

DR. BAUMEISTER: No.

VICE CHAIRPERSON McLAUGHLIN: Can you try?

DR. BAUMEISTER: Employer based health insurance.

DR. GANZ: Yes.

DR. BAUMEISTER: Is travelling away, at least the prediction is is that less than fewer and fewer employers are offering insurance. And so I just wondered what percentage of your business is through employers?

DR. GANZ: The vast majority.

DR. BAUMEISTER: And your premiums are going up and up and up?

DR. GANZ: Yes.

DR. BAUMEISTER: And up?

DR. GANZ: Yes.

DR. BAUMEISTER: And my question is I would like you to tell me what you're going to do about that?

DR. GANZ: Okay. Do you have the rest of the afternoon? First off, I don't think so much of myself to be able to say I know exactly how it ends,
this way out.

What I would say in terms of the employer. I'm not sure that the employers response to health care the way we see it today is what we're going to see in ten years, and I'm not sure we should see it the same way.

My view is is that the system needs to be responsive to individuals. The reason that I think employers continue to sponsor health plans is -- but I think they also view it in a paternalistic fashion, and I don't think this is a bad thing. I think people's hearts are in the right place. That they want their employees to be able to have access to health care. They see how expensive it's becoming and they want to try to structure it so that they can keep the costs as low as possible for themselves and their employees. That it's sort of this notion of trying to do something within a system that really isn't working.

And then there are other employers that are kind of trapped or they feel that they're trapped, would just as soon get out of health care benefits but because of either union contracts they have or relationships feel like they can't move beyond their current reality.

I think that will create distortion and
could only make things worse if we don't -- I mean, it's again why we need to step back and say what is a more rational way to structure the system in this country.

I guess I would rather see a situation in which employers facilitate rather than dictate what kind of health care or health care plans people get. And that people be allowed to -- but also with the financial account that goes with that -- to choose more what structure their health plan or benefits more to what meets their individual needs as opposed to sort of buying into a broad base. And that health plans, like us, need to compete on an individual level and not at a group level. So that maybe the group qualifies us to say yes, okay, we meet certain levels. But that ultimately who we're marketing to is to the individuals. Because I think that, again, turns our focus and keeps our focus there. Not just at the employer.

But I think in terms of the whole health care premiums going up, that is a direct reflection and is directly driven by the cost of the underlying care.

Our company, our administrative costs for example are a very small percentage of the overall, you know what we take in. We basically take in for every
dollar and we pay out in actual benefits approximately .90 cents. It's in that .90 cents that that's where -- I'm not suggesting that we don't have to continue to watch our administrative costs, and we do. And that needs to be highly exposed, and it is. And if we don't do a good job of that, then we deserve to pay the consequences of that. But where the real money and where the real focus needs to be is what -- this ever increasing .90 cents that just gets bigger and bigger and bigger every year. That's why I'm suggesting a radically different approach to how we structure health care benefits and why I'm suggesting.

DR. BAUMEISTER: Well, we were meeting in Boston and we had a public meeting. And the room was stacked with single payer people. And they came well prepared. And the mantra that was chanted that night was that .39 cents of every health care dollar in Massachusetts goes for administrative costs.

And we heard this morning Senator Wyden quote 35 percent. And then had a caveat, I don't know if it's true or not, but it's out there. And that's a lot of money.

DR. GANZ: It is.

DR. BAUMEISTER: For administrative costs.
DR. GANZ: I don't subscribe to that number, unless you also include all the administrative costs that every health care provider and their clinic and hospitals and the like; maybe you might be able to push it to that level.

DR. BAUMEISTER: Right.

DR. GANZ: But if you go to a single payer or whatever, you're still going to have that kind of--those costs are still built in. If you're looking at the cost of what, you know, insurers put into it the cost is a lot less. At least I can only speak for us as a not for profit company. That I know we watch that very closely.

But again, that feels a little bit more like pointing the finger and saying someone's a fault.

DR. BAUMEISTER: Right.

DR. GANZ: A particular party is at fault. And I think what we really need to do is step back and in a sense if you look, everyone's at fault and no one's at fault. Because we have a system that really isn't very accountable in the way that it's set up. And the worst evil that you can create is when you have really good people who create bad outcomes because the system in which they work creates that with all the best of
intentions. And I don't think it has to be that way. And I believe it can be different.

So I guess in closing what I would say, because I know that Jean is waiting to get here, is I want to applaud you for taking this on and for taking time out of your busy lives to do it. It is a worthy thing. And I urge you again to keep your perspective as a citizen. As you become more expert, as you already are becoming more expert, don't start acting like an expert. You know focus on it from the line sight of you as a patient and as a consumer. And I think if you look at it from that perspective, you're going to find the answers that will have the most long term sustainable good.

Thank you very much.

VICE CHAIRPERSON McLAUGHLIN: Thank you for your comments.

DR. BAUMEISTER: Thank you. Thank you.

(Applause).

VICE CHAIRPERSON McLAUGHLIN: Next we're going to hear from Jean Thorne, who is currently the Administrator for the Oregon Public Employees Benefit Board, which is responsible for the design, purchase and administration of benefit plans for all state employees.
and their dependents of 100,000 members. So bringing a complimentary perspective to our discussion.

Prior to this, however, she was the Director of the Department of Human Services here in Oregon. And before that was the state's Medicaid Director from 1987 to 1995 and was thus responsible for leading the implementation of Medicaid reform under the Oregon Health Plan. And in fact one of her numerous positions was working as a policy advisor for Governor Kitzhaber.

So we're sort of ending where we started, and we welcome you and look forward to these last words of advice and experience that we're hoping to get from you.

MS. THORNE: Thank you very much. It's been like a trip down memory lane today. Dr. Santa called me and asked if I would kind of finish up, so to speak, since I had been the Medicaid Director during all the Oregon Health Plan and now I'm really on the purchaser's side and to offer whatever lessons I learned. It is interesting after having been through all of this and having seen so many old friends and colleagues who have been part of a really phenomenal process in Oregon. Sometimes we get so caught up in doing it we don't step back and recognize what we've really done here. And I'm
really proud to have been part of it.

It's been interesting. I started as the state Medicaid Director just as the decision had been made to discontinue funding organ transplants, as Governor Kitzhaber talked about. We really learned a lot during that time as we went through the development and the implementation of the Oregon Health Plan. So I've been asked to talk about what it's like to go through all that and then to reflect back on what I think we've learned.

It was in 1987 that the coverage for transplants was discontinued. At the same, though, the legislature also had utilized those dollars and other dollars to expand coverage for pregnant women and children who hadn't had it up until then. But then, as Governor Kitzhaber noted, it was done very quietly. It wasn't until we began denying requests for transplants that the public and the press really became more aware of what was occurring.

And certainly we began trying to talk about the trade-offs. And that was very difficult when we were being faced at the same time with a child or others who potentially could have benefited from the organ transplant and trying to put a face on the other people
who had no health care coverage.

Then-Senator Kitzhaber was on one side of the table and I was on the other as we went through a number of legislative hearings. And I think in 1988 what was very interesting is that out of that really came much more of an awareness in Oregon that we don't have a health care policy. We had legislative hearings where I had to explain that you can do this under Medicaid, you can't do this under Medicaid. No, Medicare is something different. And, at that time there were 400,000 people without any type of health insurance in Oregon. And they were really astonished by that.

The press picked up on that as well. And once they moved past the issue of there being a child who died who potentially could have been saved, they really began looking at the underlying issues as well. And I remember the local NBC affiliate aired a documentary -- this is 1988 -- about the health care crisis and the lack of a system that we have in this state and this country. And this was really far before there was a national awareness.

In 1989, as Governor Kitzhaber noted, the framework for the Oregon Health Plan was passed. I remember sitting with him as he said well we should do
this, this and this. I said you can't do that under federal law. And he said then let's go get waivers. Okay.

We spent the next four years working on those federal waivers. The original legislation, which was passed in '89, said we'd have the program up by July 1990. And I remember saying to Governor Kitzhaber are you out of your mind. We can't do that by then. He said well if we said 1992, it would be 1994. Well, it was 1994.

We dealt a lot with the subject of rationing. We had a lot of representatives of national advocacy groups who focused on that and who said we were going to ration health care. And it was interesting to me that advocacy groups, especially, were not willing to look at the people who had been rationed out of the system entirely. And we really talked about how we were trying to bring rationality to the rationing that is occurring right now. And many of the groups who were critical had concepts of what the list was without really knowing what the list was. It got explained, as Dr. Kitzhaber noted, that we had life saving treatments that were sure to work in restoring health at the top of the list and at the bottom of the list you
had treatments that were futile or for conditions that
were self limiting. As we spent more time talking to
people about the reality of what was on the list it
really opened up the discussion more.

The national press focus was certainly
initially on rationing. And I remember many, many phone
calls asking about how many people are going to be left
to die if we implemented the list. And I often had to
try to turn that around to how many people are dying
right now because they don't have access to some of the
basic care that others may have.

I think that what you heard here today was
that Oregonians, whether they were public citizens being
part of some of the Oregon Health Decisions group, the
numbers of physicians and other providers that were part
of other processes, really were involved in creating the
plan and having ownership in that. That meant as Oregon
approached the federal government for the waivers, we
really were approaching it as a united front. It wasn't
the bureaucrats going off to try to get waivers, it was
Oregon -- Oregon as a whole working on that.

What we tried to do was to raise the issue
of the need for trade-offs. I think one of the first
questions you asked this morning of Governor Kitzhaber
was that you need to find out what services people want or need. And his reply referred to a need for first providing a framework. People need to understand and be part of trying to understand there are limits, there have to be limits. There are right now. And what has happened is that we have excluded people from coverage. How do we within the context of limits make those trade-offs?

I remember I spent a lot of time with the national press. I remember getting a phone call from the National Enquirer, it was the research department, and they wanted me to be part of a point-counterpoint. And I said, well I didn't really want to do that for the National Enquirer. But I did find myself, when I thought that National Enquirer was going to be covering it, at the grocery stand trying to look to see if it was in that issue. I didn’t want anyone to see that I was actually looking at the National Enquirer.

But there was a lot of public discussion. And I think what was especially telling and that to me said we were really doing a good job of telling the broader story was when the waivers were initially denied in August of 1992. When we received the press clippings from the clipping service within a few weeks after that,
there were 38 editorials from papers outside of Oregon; 36 of them said Oregon should have been permitted to do this.

What we continued to try to do during that time was to say that if your alternative is to do nothing, are you really satisfied with the status quo? Is it good enough to say there will be some people who will get just about everything and some people who will get nothing? So certainly having that broader perspective and articulating those trade-offs is critical to be able to move forward within a context of what it is that Americans want from the health care system.

As we implemented the Oregon Health Plan in February of '94 it was quite a time. We had basically had funding approved by the legislature for staff positions in August of '93 and had to fill positions and implement the plan by February of '94. There were three things we were doing in Medicaid.

We were fundamentally changing how benefits were designed by using a prioritized list, which meant we had all of the systems issues of condition and treatment pairs and a lot of provider education around that. We were working to establish and then transfer
almost all the Medicaid recipients into managed care plans. And we were also expanding eligibility to the federal poverty level, so we had to establish all the mechanisms to enroll members as well.

About a week after the legislative session ended -- which at that point was the longest session on history -- I had systems staff come up to me and say "Well, we don't know that we can get it done by February." And I said "No, you will get it done by February."

We had been talking for five years about the fact that there were people's lives at stake. There were people dying right now because they weren't able to access health care. And it was going to be important that we got that program up. Frankly, we brought all of our stakeholders into that and said it's going to be messy. We are going to do what we can, and that meant everyone else had to be with us on that, putting in place what we needed to put in place to bring the program up in February. That meant constant communications with our managed care plans, with the advocates; keeping everyone in the loop.

Basically I think the approach we all took was we're all in this together. This is not going to be
perfect. Yes, we were pioneers in many ways trying new and different things. We needed to work through this process together.

As we started the plan in February of '94, we knew we were going to be in the national spotlight, both from those who wanted us to succeed and those who were expecting us to fail. I think we had planned, but we weren't prepared in many ways for what we ended up hearing.

We had contracted with a call center, and we had 1-800 lines where people could call in and get basic information for their application. We had estimated we would have 5,000 calls in the first month. We had 4,000 per day for at least the first couple of weeks.

The callers didn't realize they were going to end up talking to people in California. We had to give people down in California lessons on how to pronounce the cities so they thought they were talking to someone from Oregon.

We had thought on the new eligibles, those who were newly eligible for Medicaid through the Oregon Health Plan, that it would take us 17 months -- by June of '95 -- to get 70,000 enrolled. We had 85,000 within the first six months -- by August of '94.
People were calling in tears. And having to wait a long time on those lines. And saying I have not had coverage, I need to see a doctor so badly and this is a life saver for me. And we were able to put faces then on those who hadn't had faces in the past.

Those who were looking for the big stories of health care rationing, actually didn't find it. I think two or three days after the program started I had a call from a reporter from the San Francisco Chronicle and he said "Has anyone died yet?" And I said, "Well, not that I know of." And he said "Well, have you had any requests for anything?" I said, "Well, yes, we have. I know we received one that was turned down." And he asked, kind of salivating, "What was it for?" "Well, it was for a circumcision." And he decided it wasn't that big of a story.

And really what we then saw was the change in the press focus from what are people losing to what are people gaining. I think that spoke a lot also to the list. The people who had worked on that, and they were volunteers, are heroes from my perspective. They really put together something that could stand up to public scrutiny.

Yes, we had a lot of kinks to work through.
We brought this up quickly with a lot of changes. But again, I think all of those who were part of it thought we were in this together, we will make this work.

We had a lot of advocates involved, especially a few months later when we then rolled in the SSI population. They were part of working with us and with the plans to make sure we had sure plans that were responsive to the needs of persons with disabilities. The Health Services Commission had really worked to incorporate at appropriate places treatments that were especially important to people with disabilities.

Again, I think all of those were involved in Oregon really took pride, a feeling like they were a part of this, whether it was the data entry operator in my office, or it was a physician in the community. People felt that this was an important change that Oregon was part of and that we really were trying to help Oregonians institute it a rational way.

Let me just talk a moment about the use of the list. It really was a tool to force explicit policy choices, as Governor Kitzhaber noted. And so it required the legislature to decide yes we're going to fund this much, but no more. I remember in the initial funding, initially the Legislature had put it at one
level and said before we're done with this session we
want to put more money in, but we're going to need to
decide how far beyond we can and should go given our
other needs. It really did allow policymakers to reduce
services if necessary in a much more rational manner
than you normally have available under Medicaid.

In Medicaid, you throw people off, you
discontinue whole categories of optional services. This
brought rationality to it.

I think what was especially disappointing,
though, is that even though we received federal approval
for the waivers, there really was an unwillingness of
the federal government to allow us to utilize the list
as a means to deal with budgetary shortfalls.

I remember in 1995, I wish I knew how many
hours we spent on conference calls with staff of what
was then HCFA about diaper rash treatments, because that
was one of the lines that was being proposed for
elimination. It took incredible amounts of time before
they finally said we'll allow you to eliminate that. I
went off to work for Governor Kitzhaber on education
issues for a while and it was during that time the
Administration at that time said don't even come back
and ask us. We are not going to allow you to move the
line any further.

We did with the current Bush Administration go back, and this was after the legislature, along with input from the medical directors of all the managed care plans who worked with us, had decided and made a recommendation to eliminate 35 lines of coverage. The physicians, the legislature, others said you know these are 35 lines where it is appropriate to eliminate coverage. We received approval to remove three lines So it was very clear then that how we had intended to utilize the list was not something that really was being accepted as a tool by the federal government. And, in fact, some of the decisions that we were then confronted with during the budgetary shortfalls in 2003 meant we had to go back to the elimination of the medically needy program. We went back to eliminating whole categories of services.

I think what that did affected not only the viability of the plan, but the political viability of the plan. Those who were maybe luke warm supporters in the state legislature, once we had our primary tool not really something you could use, then used that as a reason to eliminate whole categories of people from coverage. But I think the list continues to be an
important tool.

In my current role, which I'll get to in a moment, we did a request for information last year with health plans throughout the state. We asked them about the prioritized list. And almost all of them came back and said you know physicians accept this, they're used to it. And it is a legitimate tool.

Let me talk briefly about my current role and then get back to some of the lessons learned. I'm currently Administrator for the Public Employees Benefit Board, which is governed by an eight member board, half management and half labor. Three of the people you've heard from today either are or have been on our board.

The Board in late 2002 was being confronted, as other employers were, with increasing premiums. They had seen basically in the last six years, about an annual 10 percent increase in insurance premiums. At the same time our cost of living increases that are granted to state employees had averaged 1.7 percent. The Board was recognizing those trade-offs. Whether it's from a labor union perspective or an employer perspective, more and more dollars were going to health care, which really meant that even on the employee side, those dollars weren't available for compensation. And the Board
really began asking what's the value? What are we getting out of our current system? And so they established what they called their Vision for 2007, focused on systems of care, on evidence-based treatment, on outcomes rather than just provision of services, on transparency.

One of the guiding principles the Board outlined before we'd gone through a request for a proposal process to begin this in 2006, was that providers need to own this. We need to have systems where providers are going to make the changes that are necessary to focus on the patients, to focus on the outcome. This can not be merely a top down approach.

The vision guided the RFP. We went with an extensive process. We did end up with two additional contractors. But it will be difficult I think for them to gain the kind of critical mass that they will need. We are the largest employer based purchaser in the state, but the providers in those two plans were not allowed by the statewide carrier to withdraw from their provider panel for purposes of our employees. So I think it's a real question of will we be able to be a catalyst for change when we have the same providers who, in essence, may be part of two or more competing plans.
We also recognize we have challenges in engaging our own members. We've been trying to talk with them through our newsletter as much as possible about the problems with the current system and the need for improvements. But when it comes down to it when we have open enrollment next month, it will be interesting to see how many of them elect to make a change based on some of the components of the vision. So time will tell what we're able to do as the major purchaser in the state.

So let me just then talk, given that background, about the lessons learned. Actually, my first one reflects something that Mark Ganz said. What I have seen over the years is that people are trying to find somebody to blame. It's the insurer's fault, it's the physician's fault, it's those darn consumer's fault, it's business' fault; well, we are all part of the problem. We are all part of the problem, whether it's our expectations as consumers of what we expect of the system, whether it's what hospitals expect of doctors, what doctors expect of patients, what we all expect -- we are all part of the problem. And any kind of solution means that we are all going to have to make some sacrifices. And I think that in Oregon as we...
looked at the original Oregon Health Plan there was a recognition that whether it was a treatment that was no longer going to be available because it didn't do much good anyway or a provider who wasn’t going to be compensated for doing that treatment, the trade-off was that more people will then be able to gain health care coverage.

So we need to stop looking for the villain and really try to engage everyone in understanding that everyone has something, whatever their role is, that can contribute to a solution.

There aren't magic bullets. Trade-offs are necessary. What we did in Oregon was to make those very explicit.

I mentioned the prioritized list. Some, even legislators today, think oh well that's just Medicaid -- You go off and decide where the line is drawn. And we said no, you as legislators have to be accountable for those decisions. So if you really want to cover something on that list, you've got to fund all the way there. We said those were explicit decisions. It's not to be made by a bureaucracy. It's going to be made in a very public process.

The need for provider ownership to achieve
change is critical. It wasn't the lobbyists that were involved in all these efforts. It was the physicians and other types of providers. Any of this kind of change is messy. It will be messy. And the providers can make it or break it. We are talking about changing the way they do business, the way they practice and interact with their patient.

There’s the importance of credible political leadership. I've been in state government for 30 years, I know it's hard to believe I'm that old. And I would just say this: That we happened to have been blessed in 1989 by having a physician who was Senate President. And he was a physician who was willing to challenge the health care system, who was willing to say some of the things he said this morning. Who was willing to say not everything we do as a physician has evidence to support it. And he brought in other providers, other physicians along with that who said yes that's true, that we as physicians need to be part of a solution. They have an expertise and he was able to bring them along, and bring many other state officials together. So having that kind of credible political leadership is really critical to a long term solution.

Stakeholder groups can help. I think that
in some circles advocacy groups are looked at as "oh my
gosh, we've got to deal with them again." Within
Oregon, the stakeholder groups involved in this helped
to make our products better, helped to make the delivery
system better. They helped with the national advocacy
groups in trying to help them understand we're not just
talking about those who already have coverage, we are
talking about a broader group of people, of children, a
broader group of people with disabilities and others who
don't have access now. We need to be thinking about all
of them.

And lastly on lessons, media can be your
partner. Responsible media can be a partner in really
helping educate. If the public doesn't accept the idea
that trade-offs are necessary and that there are limits,
it's going to be very tough to move them.

You know, we have a more sensationalized
media now, and it may be more difficult now. But I
think within Oregon we really found that there were very
credible media partners who tried to portray the larger
picture and to do it very responsibly.

On to some of the challenges. As we all
look towards solutions, I think in many cases people
come in with their predisposed idea of here's the
approach, and it's a philosophical approach. We'll try the competitive model. The competitive model is what will be the answer. Well, in Oregon we have many areas of the state -- in fact probably most areas of the state that don't have excess physicians. Outside of the Portland area, we basically are a one hospital town around the state. And so the concept is not let's have this competition, because we don't really have enough providers to go around in most cases. Our approach is to float all boats. How do we raise the practice level, how do we raise the quality and the smart utilization of health care treatments among all providers?

We need all providers to focus on the greater good and not just what their bottom lines are. I'll come back to the lobbyists again. In the 2003 legislative session we were faced with some very, very serious financial constraints. Some legislators decided they'd just get all the lobbyists in a room together from all the provider groups and they'd come up with a solution. Well, after weeks and weeks of evening meetings, everyone was able to point to something that someone else could do to save money. I think we had a $200 million hole and they came with $3 million worth of savings. The only thing that they did all seem to agree
on was that obviously the bureaucracy needed to be changed. So they found a common enemy in us.

One of the frustrations during 2003 when we were facing some cutbacks, was hospitals who said no, we're not willing to support the inclusion of mental health and clinical dependency treatment. And I know when I talked to them I said, wait a minute -- by cutting these services you have more people in your hospital ER, you have them coming in more seriously ill. But it wasn't an issue of what was best for the system and what was best for the community. It was that the other provider group was going to get money. We've got to look beyond that. And I think we can do that with the professional leadership of our provider organizations and with individual providers. This is very difficult to do if you think the lobbyists will do it.

Another philosophical approach is to just let consumers decide it, that a consumer-based approach will solve it. Well, our Board certainly supports transparency and having more information available. But I know I'm not a health care professional. My doctors went to school many years, and I expect them to know more than I do. Even though I could ask questions, and
do ask questions, if it's up to me to go from specialist to specialist, that's not very efficient either.

I think we really have to question can all consumers or maybe how many consumers can we really expect to effectively and efficiently manage their own care. There definitely is a role for consumers to be better shoppers and have more information. But that by itself is likely not the answer.

Others will say that if all the purchasers just asked for something, that will make change occur. At PEBB, we're not that big, and we can't get critical mass. Even if we got all purchasers together -- and we do have a purchaser's coalition in Oregon -- can we really get everyone together on a single page and ask for the same things?

So as you look at various solutions, I think that you should try to not jump to a conclusion that a certain approach will just take care of it. It is much more complex than that, and you know that.

Gaining public understanding, which is what you're trying to do, of a very complex issue is a huge challenge. How do you articulate those complexities so that individuals really do understand the need for trade-offs? Because there are limited resources. And
how do we as a community, how do we ask society to best spread those resources so we can do the greatest good for the community?

And I would say that as we look to public acceptance, if you don't at the front end have acceptance from provider or stakeholder communities, you're not going to get the public to accept the need for change either. If we look at the mid-'90s at what occurred in Washington, D.C., although the proposed solution was comprehensive, when it was put forward, the groups that weren't involved were immediately out scaring people about what kind of change this was going to mean.

Somehow bringing all of those groups together to agree on a need for change, to look at the greater good and to help the public understand those complexities is certainly a huge challenge.

We learned a lot in Oregon. Often times it was the hard way. We made plenty of mistakes as we moved along. It wasn't just so easy as to go get some waivers. We didn't plan on spending eight years doing that.

This was doable in Oregon, given our size, our demographics, our political situation, our economic
situation at that time. I would say what was possible
ten, 15 years ago may certainly be more difficult now.
The politics are different in Oregon. The economy is
different in Oregon. But we feel we've learned a lot,
we continue to learn. We hope our learnings, and you've
heard from many of us today, can be helpful to you as a
struggle with these issues.

So thank you very much for inviting me and
for giving me the opportunity. It's been an interesting
pathway, and I really admire all of you for the time
you're taking and, obviously, the commitment you have to
dealing with these issues.

(Applause).

VICE CHAIRPERSON McLAUGHLIN: Aaron?

MR. SHIRLEY: A quick question out of
curiosity. A key prevention component of the Medicaid
program is the EPSDT. What impact did the waiver have
on that component.

MS. THORNE: We received a waiver from
EPSDT. Not that we wanted to -- we had a huge emphasis
on preventive care. But I think part of the problem
with EPSDT was that in the interpretation we were
receiving it was anything that potentially might be
needed for a child had to be provided. And, as I noted,
things were lower on the list that were conditions that
might have gotten better on their own or where there
were other treatments that may have done just as much
good. So that was a huge issue with the feds. Anytime
there was a proposed line change that potentially
affected a child, it was very difficult to get them to
move past that, even though we had a waiver and even
though there are other treatments that are just as
effective or maybe will take a little bit longer. So we
did receive a waiver from that, but certainly there is a
huge emphasis on prevention. It wasn't the early,
periodic, screening, or diagnoses parts of EPSDT, it was
more the treatment end, and every treatment that might
be possible.

VICE CHAIRPERSON McLAUGHLIN: Dottie?

MS. BAZOS: Can you tell us a little bit
about outcome changes after you initiated the plan, what
your studied, what you learned particularly with regard,
we'll say, to infant or infant mortality rates?

MS. THORNE: I think actually Dr. Goldberg
mentioned those -- I wish I had written them all down.
But certainly prenatal care and immunization rates went
up, infant mortality went down. There were studies
done; I think they're probably on the Office of Health
Policy and Research website. In many cases that information was self reported because we didn't have any kind of predata. It was members or clients saying what their experience or what their health condition had been before.

MS. BAZOS: And can you remind me why this plan isn't active now?

MS. THORNE: Well, kind of going back I think a key piece again is the prioritized list. I'm going to give you my taxation system in Oregon speech. Unlike most other states, we have no sales tax. We have personal income tax, but our property tax rate is limited. So instead of the three legged stool, we have 1 1/2 legs. And a system that is based on income tax is great in good times and really bad in poor economic times. And Oregon took deep, deep cuts in about 2001 forward.

And I will say, I don't believe we could have balanced the program by only using the prioritized list, but it would have given us a significant amount of savings if the federal government would have approved allowing us to make the cuts that we had proposed. They weren't willing to do that. And I think that not only was it that, but again the political situation is
different and I would say a lot of legislators by 2003
didn't really see some of the value and said well, the
Oregon Health Plan really is dead anyway because we
can't control the costs of it.

What is now called the standard population
or the new eligibles, by the time the 2003 legislative
was done, coverage for that group was going to be funded
through provider taxes on hospital and Medicaid managed
care plans. Those have been approved, but even there the
plan had to fit within the amount of money from those
taxes, so through attrition that group has to get down
to 25,000 people. We had 120,000 in that group when I
was there in the mid-90s. So I think the economics of
it and then just the inability to really use the
prioritized list as a way to help, if not completely
balance the budget, has made it very difficult to be
able to sustain the plan.

MS. BAZOS: Okay.

MS. MARYLAND: Sort of a follow-up question.

Some states have moved in the direction of provider
taxes and getting matching dollars from the federal
government. Has any thought been given to that in terms
of Oregon, and if not --

MS. THORNE: That is what we're doing,
Ms. Maryland: Thank you.

Vice Chairperson McLaughlin: Any others?

Well, I want to thank you very much for finishing what was really a wonderful day.

When we went over to lunch, we were sort of glad that we had to wait awhile for our food to show up because it gave us a chance to talk. And we really have enjoyed what was billed as a listening experience for us today. We really learned a tremendous amount.

And I would be remiss if I didn't point out that it has, to some degree, struck fear in our hearts because we're supposed to do the whole nation. But at the same time it has inspired all of us. And I started with saying that to Senator Wyden who started the day, that it gave us all a big boost. And it really has. And I want you all to know that; that we heard what you did here and it really has given us a big boost. We feel energized and are looking forward to our community meetings with more anticipation and excitement than I thank we had before.

So this was a very worthwhile day for us, and we're very grateful to you. So thank you for
coming.

And I believe that's it. Thank you.

(Whereupon, the working group meeting was adjourned.)