

Mr. KENNEDY. Just for 30 seconds, Mr. President.

The PRESIDING OFFICER. The Senator from Massachusetts.

Mr. KENNEDY. Mr. President, at the outset, I see my chairman, Senator ENZI, who has taken the chair of our committee. I commended him for bringing this legislation up, and I say to you, Mr. Leader, we thank you for your willingness to schedule this legislation. It is of enormous importance. We have had a good debate and discussion about all of the concerns families are faced with without this kind of protection. We thank you very much, and Senator REID, for getting this legislation up and giving us a chance to express the Senate view on this matter.

The PRESIDING OFFICER. The majority leader.

### ORDER OF BUSINESS

Mr. FRIST. Mr. President, for the information of Members, we will be voting in a few moments on the genetic nondiscrimination bill. For the remainder of the day, we will be working on the Lebanon resolution, the committee funding resolution, and some military nominations that have been reported by the Armed Services Committee.

As I mentioned earlier this morning, we will convene tomorrow for the reading of Washington's Farewell Address. However, we do not expect any business to be transacted tomorrow.

We are hoping to begin consideration of the bankruptcy bill that was passed out of the Judiciary Committee today when the Senate returns following the President's Day break. I will be working with the Democratic leader on that agreement and will announce more on that later today.

We have had a good week of work, completing action on the Chertoff nomination, the Nazi War Crimes Working Group extension, the nomination of Robert Zoellick and, in a moment, passage of the nondiscrimination legislation.

Having said that, I hope and expect that this will be the last vote of this week. I want to discuss a few items with the Democratic leader, and we should be able to announce shortly whatever other plans are for later today.

### GENETIC INFORMATION NONDISCRIMINATION ACT OF 2005— Resumed

The PRESIDING OFFICER. The clerk will report the bill by title.

The assistant legislative clerk read as follows:

A bill (S. 306) to prohibit discrimination on the basis of genetic information with respect to health insurance and employment.

Mr. FRIST. I ask for the yeas and nays.

The PRESIDING OFFICER. Is there a sufficient second?

There is a sufficient second.

The question is on the passage of the bill.

The clerk will call the roll.

The assistant legislative clerk called the roll.

Mr. MCCONNELL. The following Senator was necessarily absent: the Senator from Pennsylvania (Mr. SPECTER).

Mr. DURBIN. I announce that the Senator from Delaware (Mr. BIDEN) is necessarily absent.

I further announce that if present and voting, the Senator from Delaware (Mr. BIDEN) would vote "yea."

The PRESIDING OFFICER (Mr. COLEMAN). Are there any other Senators in the Chamber desiring to vote?

The result was announced—yeas 98, nays 0, as follows:

[Rollcall Vote No. 11 Leg.]

YEAS—98

Akaka	Dole	Martinez
Alexander	Domeneici	McCain
Allard	Dorgan	McConnell
Allen	Durbin	Mikulski
Baucus	Ensign	Murkowski
Bayh	Enzi	Murray
Bennett	Feingold	Nelson (FL)
Bingaman	Feinstein	Nelson (NE)
Bond	Frist	Obama
Boxer	Graham	Pryor
Brownback	Grassley	Reed
Bunning	Gregg	Reid
Burns	Hagel	Roberts
Burr	Harkin	Rockefeller
Byrd	Hatch	Salazar
Cantwell	Hutchison	Santorum
Carper	Inhofe	Sarbanes
Chafee	Inouye	Schumer
Chambliss	Isakson	Sessions
Clinton	Jeffords	Shelby
Coburn	Johnson	Smith
Cochran	Kennedy	Snowe
Coleman	Kerry	Stabenow
Collins	Kohl	Stevens
Conrad	Kyl	Sununu
Cornyn	Landrieu	Talent
Corzine	Lautenberg	Thomas
Craig	Leahy	Thune
Crapo	Levin	Vitter
Dayton	Lieberman	Voinovich
DeMint	Lincoln	Warner
DeWine	Lott	Wyden
Dodd	Lugar	

NOT VOTING—2

Biden Specter

The bill (S. 306), as amended, was passed.

Mr. DOMENICI. Mr. President, I am pleased to have supported the "Genetic Information Nondiscrimination Act of 2005," a bill that will prohibit discrimination based on genetic information with respect to employment and health insurance. This bill represents much cooperation on the part of my colleagues, and I want to thank them for all the hard work done on this important issue.

I am extremely pleased with today's passage of the Genetic Information Nondiscrimination Act as it marks a great milestone for those of us involved in the Human Genome Project. It seems only a short time ago that the Human Genome Project was created as a joint effort between the Department of Energy and the National Institutes of Health. What progress we have made.

In the last 2 years, there have been many events celebrating the completion of maps of the human genome. The

genome map has brought a promise of improved health through revolutionary new treatments for illness and disease. The ultimate result of mapping the human genome is a complete genetic blueprint, a blueprint containing the most personal and most private information that any human being can have. We will now have a wealth of knowledge of how our countless individual traits are determined. And perhaps more important, we will have fundamental knowledge about the genes that can cause sickness and sometimes even death.

Our personal and unique genetic information is the essence of our individuality. Our genetic blueprint is unique in each of us. However, as genetic testing becomes a more frequently used tool, we now must begin to address the ethical and legal issues regarding discrimination on the basis of genetic information. Questions regarding privacy and confidentiality, ownership and control, and consent for disclosure and use of genetic information need to be carefully considered.

An unintended consequence of this new scientific revolution is the abuses that have arisen as a result of our gathering genetic information. Healthy people are being denied employment or health insurance because of their genetic information. By addressing the issue of nondiscrimination, we are affirming the right of an individual to have a measure of control over his or her personal genetic information.

Genetic information only indicates a potential susceptibility to future illness. In fact, many individuals identified as having a hereditary condition are, indeed, healthy. Some people who test positive for genetic mutations associated with certain conditions may never develop those conditions at all. Genetic information does not necessarily diagnose disease. Yet many people in our society have been discriminated against because other people had access to information about their genes, and made determinations based on this information that the individual was too risky to ensure or unsafe to employ.

While the issue is complex, our objective is clear; people should be encouraged to seek genetic services and they should not fear its discriminatory use or disclosure. The Genetic Information Nondiscrimination Act is an important first step toward protecting access for all Americans to employment and health services regardless of their genetic inheritance. There is simply no place in the health insurance or employment sector for discrimination based solely upon genetic information.

### GENETIC INFORMATION NONDISCRIMINATION ACT OF 2005

Mr. ENZI. Mr. President, I rise to speak on the promise of genomics.

"Dazzling thrilling astonishing breathtaking". Even for a group given to hyperbolic speech, the language my

colleagues used in this Chamber 2 years ago to describe advances in human genetics is both extraordinarily intense and factually accurate. Little has changed since 2003. Indeed, little has changed in the 9 years we have been considering this legislation. What remains the same is that the tremendous promise of this fundamental scientific advance remains incompletely realized. I am truly concerned that, at the very time in healthcare that we need innovation the most, we tacitly accept limitations on the application of this “tremendously powerful tool.”

It is vital to understand that we have hurtled forward, over a remarkably short period of time, into an entirely new era of medical practice, one the majority leader believes will be characterized by “advances . . . more dramatic than any . . . I had the opportunity to . . . participate in over twenty years in . . . medicine”. Barely 50 years ago, Drs. James Watson and Francis Crick completed the work begun by the 19th century Austrian monk, Gregor Mendel, when they discovered the double-helix structure of DNA, the substance of which genes are composed. Four nucleotides, a simple combination of phosphate, nucleic acids and sugar, are arranged in an infinite variety of pairs within genes that, in turn, are distributed amongst the 46 chromosomes, which constitute the normal human genome. Operating according to the instructions contained in the DNA, cells in the body produce proteins that control the expression of our individual heredity, e.g. color of hair and eyes, and determine, in part, whether we will be sick or well.

Hardly 2 years ago, Dr. Francis Collins and colleagues at the NIH National Human Genome Research Institute completed mapping of the human genome, determining the exact location of the 3.1 billion base pairs that constitute our “blueprint of life”. It is encouraging to note that, in an era where government programs are beginning to receive the scrutiny the public deserves regarding results, this program completed its Herculean task 2 years ahead of schedule. As representatives of the people, we now have the opportunity and the responsibility to help scientists and clinicians bring this basic research forward to the hospital, the clinic, even to our very workplaces and homes. There are many, both sick and well, who are counting on us to help put that blueprint to use.

How does the science of genetics, simple and straightforward as it may be to the experts, translate into something with meaning to those outside the scientific community: the Congress; and the citizens whom we represent? In particular, why should the rancher in Cody or small businessman in Gillette care? I can think of three ways.

First, our Declaration of Independence states that we are “endowed by our Creator with . . . unalienable rights (including) life, liberty and the

pursuit of happiness”. Clearly, the state of our health can determine how successfully we exercise at least two of those rights. For example, patient care can be much more individualized if it is based on an understanding of the human genome. Current medical practice applies the results from studies obtained in groups of patients to the treatment of the individual; within each group, however, there are patients who respond better or worse to the therapy offered, compared to the response of the group as a whole. The former may be undertreated by standard therapy—they could recover faster or more completely, while the latter may be overtreated—developing complications of therapy that may prove worse than the disease itself. Providers need a way to predict what an individual’s response to treatment is likely to be so that a particular course of therapy can be modified intelligently and expeditiously. That flexibility in treatment, guided by an understanding of the patient’s unique, genetically determined response, should result in better outcomes. Even today, oncologists are treating cancer patients with protocols that take into account genetically determined differences in how individuals absorb, metabolize and excrete drugs. Drug therapy for other diseases should show similar, clinically relevant variability. Similarly, cardiologists caring for patients with hereditary long QT-interval syndrome, a disturbance in heart rhythm that can lead to sudden death in healthy young people during exercise, are beginning to use genetic testing to help select patients for treatment or observation and to choose amongst the therapeutic options available—lifestyle changes, drug therapy and surgery—the ones most likely to be of benefit.

Second, we recognize, based on long experience, that prevention is better than cure, both for the individual and for society as a whole. Early identification of a genetic predisposition to develop a specific disease can be crucial to an effective intervention, one that, quite often, will be less costly, too. For example, cystic fibrosis—an inherited disease producing life-threatening digestive and respiratory symptoms—is the most common, recessively inherited condition afflicting white American children. Scientists have identified over 700 genetic variations of cystic fibrosis, some of which help to define the clinical manifestations of the disease. Treatment programs for cystic fibrosis that emphasize preventive therapies are associated with the best outcomes. Early identification of those at risk and more precise characterization of what those risks will be facilitates a more productive program of monitoring, more aggressive preventive care and focused treatment. Likewise, sickle cell anemia, an inherited abnormality in the production of hemoglobin, the molecule in the blood that carries oxygen to the cells, is prevalent in African Americans. Sickle

cell disease, the most severe variant of this condition, carries a significantly increased risk of disability and early death through a variety of infectious and thrombotic complications. Changes in lifestyle and compliance with regimens of preventive care, e.g. prophylactic antibiotic therapy, are easier for affected individuals to tolerate if they believe that the risks and benefits really apply to them.

Some might argue that diseases like these, though unquestionably worthy of public attention, represent a lesser national priority when compared to the other health care needs. In addition, other pressing domestic and international concerns—deficit reduction and national security—figure prominently, as they should, in the national debate. Wyoming has relatively few citizens at risk for some of the diseases I highlighted today, so most citizens of my state might, understandably, focus their thoughts elsewhere.

I think there are two reasons why they don’t. The people of Wyoming take appropriate responsibility for one another’s well-being. They lend a hand whenever help is necessary, not in the expectation that to do so will be of direct benefit to them, but because it is, simply, the right thing to do. There is a direct benefit, however, to be realized. Full implementation of the results of the human genome project will have a revolutionary impact on diseases that are of concern to all of us, in Wyoming and across the United States, regardless of our age, gender, or ethnicity. Already, experts recognize the practical and the potential applications of genetic research to the diagnosis and treatment of cancer—e.g., breast, colorectal and ovarian—heart disease, degenerative neurological disease—e.g., Alzheimer’s and Parkinson’s—diabetes, and asthma. No longer is it science fiction to anticipate that primary healthcare providers will, by combining environmental risk assessment and education with genetic evaluation, be able to develop, implement and monitor a comprehensive, life-long health plan that maximizes wellness.

Third, and, perhaps, most important of all, Americans must recognize that they have a civic responsibility not only to care for their own health, but to participate in the research yet to come that moves the science of healthcare forward for everyone. Those of us, including myself, who have contributed to this discussion over the last 9 years have all noted the remarkable “explosion of knowledge” and the “great strides” in healthcare that have resulted from research already performed. More importantly, though, we recognize that, while the science of human genomics has ushered in a new era of vast potential, that promise has not yet been fully realized. There is much that remains to be done to “unleash the power” of this science to change permanently the practice of healthcare for the better. Clinical trials are still necessary, to validate

reasonable hypotheses and to determine where innovations should fit into practice. Once integrated, the actual effect of these innovations must be accurately and precisely assessed, recognizing that experience is the great teacher. We must work to foster a culture of enlightened self-interest in the American people, underscoring their altruistic motivation to do what's right. Finally, we have a responsibility to encourage our fellow citizens to participate fully in their own healthcare by working with their providers to incorporate advances in science into their personal health plans as quickly as possible.

Inherent in discharging this responsibility is the need to remove barriers to action. Thomas Jefferson said, "Laws and institutions must go hand in hand with the progress of the human mind." No better example of this truism exists than the challenge we face in fulfilling, completely, the promise of the genomic revolution. Our objective is clear: to encourage people to seek genetic services, and to participate in essential genetic research, by reducing fears about misuse or unwarranted disclosure of genetic information.

I applaud my colleagues in voting for the Genetic Information Non-discrimination Act of 2005.

The PRESIDING OFFICER (Mr. ISAKSON). The Senator from Oregon.

#### MORNING BUSINESS

Mr. WYDEN. Mr. President, I ask unanimous consent that there now be a period of morning business, with Senators permitted to speak for up to 10 minutes each.

The PRESIDING OFFICER. Without objection, it is so ordered.

#### PRESCRIPTION DRUG PRICES

Mr. WYDEN. Mr. President, getting a good deal for our senior citizens on prescription medicines is too important for word games. In the public debate over the prescription drug benefit, it is regrettable, because the administration seems to be confusing the matter of negotiation to get the seniors a good price with what constitutes price controls. This afternoon I would like to set the record straight.

First, I want to be clear: I am against price controls for this program. I am not in favor of mandating prices. I am against the whole concept. But what I have been talking about over the past 3 years, particularly with the bipartisan legislation I have with Senator SNOWE, is negotiating, which has Medicare sitting down and negotiating for the millions of older people who are going to be relying on this benefit in the years ahead.

If anybody is not sure what negotiating is, if anybody can't tell the difference between negotiation and price controls, I want to be specific about what constitutes negotiation. First, with negotiation, you simply sit down

at the table. You say to the people you are negotiating with: I am one of your best customers. And third, you say: So, buddy, what are you going to do for me. And this, of course, is what goes on in the private sector in Minnesota, in Oregon, in Florida, every part of the country.

To tell the truth, I guess I have more faith in the folks over at Medicare than they do in themselves, because I noted that the Medicare chief actuary said yesterday this kind of negotiating power isn't going to do anything, isn't going to produce any savings, and talked about how this was going to lead to price controls and that sort of thing.

I happen to think that Medicare, through their talented folks, does have the ability to negotiate better prices, as does the private sector. But if they don't think they do, they can bring in some negotiators who make sure that the older people do get a good deal.

The story that has been trotted out in the last 24 hours is about previous and fruitless negotiations for other drugs. Cancer drugs have been cited, for example. I think that is comparing apples to oranges. There wasn't any negotiation in the past. Medicare paid up. Medicare paid up, and that was the end of it.

What I hope the Senate will see is that there is a real distinction between the kind of bargaining power Senator SNOWE and I want to see this program have at a critical juncture and the notion of price controls, which we do not support and oppose strongly.

It comes down to whether the Senate wants Medicare to be a smart shopper. I have said that Medicare purchasing of prescription drugs is like the fellow in Price Club buying toilet paper one roll at a time. Nobody would go out and do their shopping that way. Yet that is essentially what the country faces, if there are no changes at all.

One other point on this issue is also worth noting. Yesterday Secretary Leavitt came to the Finance Committee and was asked by me and Senator SNOWE and others about this question of how to contain costs for prescription drugs. The Secretary said he was hopeful that in July and August Senators and Members of Congress and others would go home and make the case to constituents this was a good program and that older people and their families would sign up for the benefit. I said to the Secretary during the course of questioning, as somebody who voted for the benefit, I hoped that was the case, that folks would sign up, but that the big barrier to older people signing up is they were skeptical that the costs would be restrained. Older people were concerned about the costs of medicine in Georgia and Oregon and everywhere else.

The Secretary's comment was: Well, there are going to be plenty of private plans, and the private plans are going to hold the costs down.

My response was, I certainly hope that is the case. That was one of the

reasons I felt it was important to get started with the program and why I voted for it. But I pointed out to the Secretary that may be the ideal, but what would be done in areas where there weren't a number of private plans and the opportunity to hold the costs down. That will certainly be the case in areas where there are what are called fallback plans. My guess is in rural Georgia and rural Oregon, we are going to see a number of those fallback plans because those are communities where you are not going to see multiple choices for the seniors. You will be lucky to have one plan, if there is to be any coverage for the older people.

What Senator SNOWE and I have said is that at a minimum, let's make sure in those areas where the older people don't have any bargaining power, it is possible for the Government to step in and make sure seniors and taxpayers can get the best possible deal on medicine.

In effect, what Senator SNOWE and I have been talking about is the position of Mr. Leavitt's predecessor, Secretary Thompson. At Secretary Thompson's last press conference he said, almost verbatim, that he wished the Congress had given him the power Senator SNOWE and I believe is important for this program.

In saying so, the Secretary made it clear, also, he was not for price controls; he wasn't interested in a one-size-fits-all approach to containing costs. He simply made clear that if it is apparent in a community that the older people won't have any bargaining power at all because choices are limited, the Secretary wanted essentially a kind of fallback authority, which would mean the Government at that point could make sure the older people and taxpayers were in a position to have some leverage in the marketplace.

I asked the Secretary why he disagreed with his predecessor. I asked specifically: Why do you see it differently than Secretary Thompson? Essentially, he said he simply believes in the marketplace, and there are going to be lots of choices. I hope he is right. I know he is certainly sincere in his views.

What I am concerned about is, I think it is going to be very hard for the Senator from Georgia and other colleagues to go home in July and August and get the older people to sign up for this program if they don't see this body is taking additional bipartisan steps to control costs. The older people are reading the newspaper and walking into their pharmacies, and they are seeing what is going on.

Regrettably, the cost of the program has continued to go up. We can debate how much it has gone up. I am not interested in some kind of partisan wrangle on it. But the cost of the benefit has gone up. And the number of seniors who have signed up for the first part of the benefit was really very low. So what this has created is a situation for