



United States  
of America

# Congressional Record

PROCEEDINGS AND DEBATES OF THE 107<sup>th</sup> CONGRESS, FIRST SESSION

Vol. 147

WASHINGTON, MONDAY, JUNE 18, 2001

No. 84

## Senate

The Senate met at 1 p.m. and was called to order by the President pro tempore [Mr. BYRD].

The PRESIDENT pro tempore. The prayer will be led today by the Chaplain of the U.S. House of Representatives, Father Daniel Coughlin.

### PRAYER

The guest Chaplain offered the following prayer:

Almighty and eternal God, Your faithfulness endures forever; Your love is ever creative. Your blessings have enriched this Nation throughout its history even to this present moment.

Each State represented in this assembly is unique in its identity and its resources. Blessed with people of diversity and freedom, each State has chosen Members of this House to represent its interests, let its voice be heard, and bear its will upon the future of this great Union.

Bless each Member of this Senate with prudence, justice, fortitude, and integrity. Lord, by lively exchange and through working together, may they discover the common ground of this Nation. Then, loosened by the bonds of history and mutualism, may they fortify this Republic and its future.

With Your grace, may there be a new manifestation in our time of these States united in justice and freedom as a peacemaker in the world, both now and forever. Amen.

### PLEDGE OF ALLEGIANCE

The PRESIDENT pro tempore led the Pledge of Allegiance, as follows:

I pledge allegiance to the Flag of the United States of America, and to the Republic for which it stands, one nation under God, indivisible, with liberty and justice for all.

### RESERVATION OF LEADER TIME

The PRESIDENT pro tempore. Under the order previously entered, the leadership time is reserved.

### MORNING BUSINESS

The PRESIDENT pro tempore. Under the previous order, there will now be a period for the transaction of morning business with Senators permitted to speak therein for up to 10 minutes each.

### RECOGNITION OF THE ACTING MAJORITY LEADER

The PRESIDENT pro tempore. The Democratic whip is recognized.

### SCHEDULE

Mr. REID. Mr. President, as you have announced, there will be morning business during the afternoon. There will be no rollcall votes today. Tomorrow we have every intention of bringing up the Patients' Bill of Rights. All Members should expect some long nights this week and next week prior to the Fourth of July break. It is the expectation of the majority leader that we finish the Patients' Bill of Rights before the Fourth of July break. So there will be rollcall votes throughout the remainder of the week.

### MEASURE PLACED ON CALENDAR—S. 1052

Mr. REID. Mr. President, there is a bill at the desk due its second reading. I now ask unanimous consent that the bill be read a second time, but I would object to any further proceedings with respect to the bill at this time.

The PRESIDENT pro tempore. The clerk will read the bill for the second time.

The legislative clerk read as follows:  
A bill (S. 1052) to amend the Public Health Service Act and the Employee Retirement Income Security Act of 1974 to protect consumers in managed care plans and other health coverage.

The PRESIDENT pro tempore. There being an objection to any further pro-

ceedings on the bill, the bill will be placed on the calendar.

### H.R. 1—FURTHER MODIFICATION OF AMENDMENT NO. 549

Mr. REID. Mr. President, I ask unanimous consent that, notwithstanding passage of H.R. 1, it be in order for the previously agreed to amendment No. 549 to be further modified with the changes that are now at the desk.

The PRESIDENT pro tempore. Is there objection? The Chair hears none, and it is so ordered.

The amendment (No. 549), as further modified, is as follows:

“(A) AMOUNT.—In determining the amount of a grant awarded under this subsection; the Secretary shall consider the cost of the modernization and the ability of the local educational agency to produce sufficient funds to carry out the activities for which assistance is sought.

“(B) FEDERAL SHARE.—The Federal funds provided under this subsection to a local educational agency shall not exceed 50 percent of the total cost of the project to be assisted under this subsection. A local educational agency may use in-kind contributions, excluding land contributions, to meet the matching requirement of the preceding sentence.

“(C) MAXIMUM GRANT.—A local educational agency described in this subsection may not receive a grant under this subsection in an amount that exceeds \$5,000,000 during any 2-year period.

“(5) APPLICATIONS.—A local educational agency that desires to receive a grant under this subsection shall submit an application to the Secretary.”

Mr. REID. I thank the Chair.

The PRESIDENT pro tempore. The Senator from North Dakota, Mr. DORGAN, is recognized for 10 minutes.

### PATIENTS' BILL OF RIGHTS

Mr. DORGAN. Mr. President, I would like to speak today about the Patients' Bill of Rights, or the Bipartisan Patient Protection Act, which we are going to be turning to beginning tomorrow morning in the Senate. This

• This “bullet” symbol identifies statements or insertions which are not spoken by a Member of the Senate on the floor.



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debate revolves around the development of for-profit health care and the growth of big managed care organizations and what that has meant to patients and people around this country who seek medical help. For some 4 years now we have been debating what has been happening with the explosion of HMOs in our health care system.

All of us understand the basics of medicine. That is, we understand that if you have a medical affliction, you need to go see someone who is trained in the field of medicine. Often, they perform certain tests, and if you have an acute problem, often they check you into a hospital to get the needed treatment in those circumstances.

But things have changed in recent years in this country. The emergence of for-profit managed care organizations that are now in charge of health care for a good many Americans has changed the delivery of health care. The delivery of health care to individual patients now does not just involve the delivery of health care advice from a doctor to a patient in an examining room. It is more than that. In some cases, we now have someone in an insurance company office 1,000 miles away perhaps, who is making a decision about what medical care they will cover and what they will not cover with respect to this particular patient.

In recent years, Congress began to get a great deal of mail from patients saying: I had a health care plan only to discover that, when I became very sick and needed the benefits of that plan, those benefits were not available to me. Not only was I required as a patient to fight a battle with cancer, I was also required, they write, to fight a battle with cancer and then a battle with my managed care organization to give me the treatment I needed.

So we will soon have before us a bipartisan Patients' Bill of Rights, or Bipartisan Patient Protection Act. Yes, it is bipartisan. Democrats and Republicans are together bringing a bill to the floor of the Senate, saying we need to change what is happening in the delivery of health care in a way that provides fundamental rights to patients.

Let me describe some of those rights. Patients ought to have the right to know all of their medical options for treatment, not just the cheapest medical option. Second, a patient ought to have the right to "medically necessary" care without some arbitrary interference by an HMO or a managed care organization. Doctors and patients, not health plan executives, ought to determine the care that is needed.

Patients ought to have the right to choose the doctor they want for the care they need, including especially specialty care.

Patients ought to have the right to emergency room care when they have an emergency.

A patient ought to have the right to have access to prescription medicine that the doctors say are medically necessary for the patient.

You ought to have the right to a fair and speedy process for resulting disputes with your health care plan or your managed care organization.

And, finally, you ought to have the right to hold that managed care organization or health care plan accountable if its decision results in injury or even death.

As this debate gets underway, we will hear a lot of things about this bill. We will hear that this is "a trial lawyer's bill of rights." God forbid, they will say, that we should give patients the right to go to an attorney and seek redress against a managed care organization that didn't do right by them.

I find this a fascinating description of this bill. I will talk a bit more about it later. But those who will come to the floor of the Senate and talk about their concern about lawyers being involved are concerned only for one side. They say: We don't want patients to have the ability to go to a lawyer to get legal help to demand that managed care organizations give them the care they need and the care they thought was guaranteed to them; let's not allow patients to have a lawyer.

They don't say anything about the managed care organizations. Those big organizations have all kinds of lawyers working for them. If a patient doesn't pay a bill, or a monthly premium, guess what? The managed care organization can certainly go and hire a lawyer. Right? They have a battery of lawyers with whom to pursue their objectives. Those who oppose this legislation say the patient ought not have the right to seek redress.

I would like to go through a few examples today and draw some conclusions. As I do that, I would like to point out that these examples are real people. I have used some of them before, and some are new. But let me describe the problems we are trying to address with this legislation through the patients and the difficulties these patients have been forced to go through in order to get the medical help they thought they were going to get under their managed care plan.

Let me turn to James Adams. I have spoken of James Adams before on the floor of the Senate. This is a picture of James Adams, the happy and healthy little fellow tugging on his sister's shirt sleeve to get her attention. He lost both of his hands and legs.

James Adams is now 7 years old. Because of his parents' HMO rules, what happened to him in March of 1993 when he was only 6 months old changed his life forever. He was suffering from a 105-degree fever. His mother took him to the family's HMO pediatrician, who diagnosed a respiratory ailment for this young fellow and a postnasal drip and prescribed saline drops, vaporizer use, and Tylenol. The pediatrician told the mother not to worry, that high fevers in young children don't necessarily mean a serious illness.

Late that night, his temperature was still rising and he was in great discom-

fort. His worried mother called the HMO. The nurse on duty recommended bathing this young fellow in cold water. The pediatrician then placed a follow-up call advising the parents to bring James to an HMO participating hospital 42 miles away, even though there were 3 closer hospitals.

On the way to the furthest hospital, which was the HMO hospital 42 miles away, this young boy suffered full cardiac and respiratory arrest and lost consciousness. The parents passed three hospital emergency rooms before they could finally reach the HMO hospital, which is where they would have coverage, according to their HMO.

Upon James' arrival, doctors were able to return his pulse and breathing. But the circulation to his hands and feet had been cut off and could not be returned, causing irreparable damage to his extremities. The result? Both of his hands and feet had to be amputated. That rendered him into a situation he will have to live with for all of his life. The delay in care caused by driving almost an hour to an affiliated hospital took its toll.

One asks the question: Is it a reasonable thing to have a young boy with a 105-degree fever go to a hospital 42 miles away and pass 3 hospitals on the way? That is the way some HMOs work. That is not the way a plan should work. Any emergency room ought to be available to this young fellow in an emergency.

Let me describe another story, dealing with another person who was denied coverage to emergency room care.

Jacqueline Lee lives in Bethesda, Maryland. A lover of the outdoors, she took a trip to hike in the Shenandoah Mountains in the summer of 1996. While walking on one of the trails, she lost her footing, and plummeted off of a 40-foot cliff to the ground below. Luckily for Jacqueline, she was quickly airlifted from the mountain to a hospital in Virginia. Amazingly, she survived the fall, sustaining fractures in her arms, pelvis, and her skull.

After she survived and went through a convalescence, her HMO refused to pay more than \$10,000 in emergency room bills because it said this woman who was brought into an emergency room on a gurney, unconscious, did not get preapproval for using emergency room services.

Because an unconscious patient falling off a 40-foot cliff, suffering substantial injuries, did not get preapproval, the managed care organization said it would not pay the emergency room fees. This is an example of emergency room care that is needed by a patient who had protection under her health plan only to be told later that she wouldn't be covered for emergency room treatment. Is that something patients should worry about? They shouldn't have to worry about that.

Our Patients' Bill of Rights says emergency room treatment is available in emergencies under what is called a prudent layperson standard of defining what an emergency is.

Let's not have more delay and all kinds of shenanigans by the managed care organization to see how it can withhold treatment. Let's say that if you have an emergency and you are covered by a managed care plan, you deserve the right to be treated at an emergency room. It ought to be true for Jacqueline Lee. It ought to be true for James Adams. It ought to be true for every patient covered under a plan who needs emergency room treatment.

Let me describe the situation of Ethan Bedrick. I have spoken of Ethan before.

The reviewing doctor never met with the family and never met with this young boy, Ethan. He simply said: Only a 50-percent chance of being able to walk by age 5 is a "minimal benefit" and therefore his insurance company would not continue the therapy.

Ethan Bedrick was born on January 28, 1992. His delivery went badly, and as a result of asphyxiation, he has suffered from severe cerebral palsy and spastic quadriplegia, which impairs motor functions in all his limbs. Ethan was put on a regimen of intense physical, occupational and speech therapy to help him overcome some obstacles throughout his development.

At the age of 14 months, Ethan's insurance company abruptly cut off coverage for his speech therapy, and limited this physical therapy to only 15 sessions per year. This change was recommended by an insurance company doctor performing a "utilization review" of Ethan's case. The reviewing doctor cited a 50 percent chance that Ethan could walk by age 5 as a "minimal benefit" of further therapy.

Ethan's parents appealed to the courts. The courts said:

It is as important not to get worse as it is to get better. The implication that walking by age 5 . . . would not be "significant progress" for this unfortunate child is simply revolting.

Unfortunately, during the time of court action, Ethan lost three years of vital therapy. And even then, the Bedricks were left with no remedy for compensation for Ethan's loss of therapy.

Does this child need patient protections? You bet your life. This child and his family need patient protections.

Let me describe a young boy named Christopher Roe. I was holding a hearing one day in Las Vegas, NV, with my colleague, Senator REID. Christopher's mother, Susan, came to the hearing, and she held, above her head, a picture the size of the one I have in the Chamber. Susan began to speak about her son Christopher and this subject of patients' protection.

His mother said that Christopher Thomas Roe died October 12, 1999. It was his 16th birthday. The official cause of Christopher's death was leukemia. But Susan said the real cause of Christopher's death was that the family's health plan denied him the chemotherapy drug he needed. Yes, it was investigational, but it would have

given him a chance at life; and it was denied at every step of the way.

Christopher was first diagnosed with leukemia in 1998. He at first achieved remission, only to develop an early relapse. His pediatric oncologist recommended he receive a bone marrow transplant, which was his only hope for long-term survival. But before he could receive a bone marrow transplant, he needed to go into a second remission.

Chris's oncologist felt that because of his early relapse, he needed an additional drug that the oncologist recommended. It was available at the Hughes Institute in St. Paul, MN, but it had already proven effective in fighting the specific kind of leukemia cells young Christopher had.

The health plan denied treatment saying, no, this drug is experimental, even though it wouldn't have had to pay for the drug itself, only the blood draws, physician visits, and blood products it would have paid for had he received traditional chemotherapy.

Chris's family immediately appealed. The review, which was supposed to have taken 48 hours, took 10 days. Meanwhile, as the appeal dragged on, Christopher's condition worsened, and his oncologist felt he had no choice but to start Christopher on the more traditional chemotherapy. But that did not work.

The National Bone Marrow Donor Program found six perfect matches for this young boy, which is almost unheard of. Unfortunately, he was never able to make it to a bone marrow transplant because he was never able to achieve the second remission without the drug he needed in order to do that. At a hearing that I held with my colleague, Senator REID, his mother Susan stood up and held this picture of young Christopher above her head, and she began crying as she described her son's death. She said: My son was 16 years old. And he looked up at me from his bed and said: Mom, I just don't understand how they could do this to a kid.

This mother felt that her son deserved every opportunity, deserved a fighting chance against his disease. What she said was: My son and our family had to fight the cancer and fight the managed care organization at the same time, and that is not fair.

She is right about that. We ought not have this happen in our country. I hope that, in the name of Christopher Roe and so many others, we can pass a patients' protection act in this Congress that says to them and others like them: You have certain rights as patients. Right now the odds are stacked. We have the big interests over here, and they have all the money and all the lawyers; and we have the patients over here who, alone with their families, are left to fight the battle.

We had a hearing in Washington, DC, about a year ago. A mother from New York came to that hearing. Mary Lewandowski was her name. I will never forget her because she came up

to me after the hearing and gave me a big hug, and we talked about her daughter Donna Marie. Donna Marie died February 8, 1997. Her mother Mary has made it a cause to try to see if she can prevent from happening to others what happened to her child. Mary comes to Congress at her own expense. Nobody pays her way here. Every chance she gets, she comes to talk about her daughter.

The week of her daughter Donna's death, she had been to a doctor four times in 5 days. Despite her worsening symptoms, this young girl was told that she had an upper respiratory infection, and she had panic attacks, her doctor said. She was 22 years old. On the evening of February 8, Donna was in a tremendous amount of pain. Her mother called the hospital, and was told she could not bring her daughter to the hospital unless it was a life-or-death situation, or unless she had a doctor's referral.

Mary tried in vain to reach Donna's doctor. One hour later, Donna lapsed into a coma and died. She died from a blood clot on her lung the size of a football.

Donna's doctor later told her mother that a \$750 lung scan might well have saved her daughter's life. But the test was not performed because it could not be justified to the HMO or the managed care organization.

Now I would like to turn, just for a moment, to a couple of other issues in this debate. The question of whether care is "medically necessary" is often cited as a reason for lack of treatment by a managed care organization.

This is a picture of a young baby born with a horrible problem, a cleft upper lip: A terrible disfigurement. Surgeons tell me that—in fact, one Member of Congress, who is an oral surgeon confirms this—it is not unusual at all to be told that fixing this is not "medically necessary" and, therefore, the health care plan will not cover it. It is not "medically necessary" to fix this. Can you imagine being told that as a parent?

Let me show you a picture of what it looks like when you fix this problem. This picture shows what that young child can look like when that problem is fixed.

After looking at the results, can one really say it is not medically necessary to fix this? This legislation begins to define what the rights of patients are with respect to what is "medically necessary."

Is it necessary for us to pass this legislation? In the name of all of these children, in the name of these patients and in the name of these people who have to fight dread diseases and their managed care organizations at the same time, the answer clearly is yes. We ought to give them those opportunities. And those opportunities exist in this legislation.

This will be a long and difficult debate. I do not know whether the votes will exist at the end of this debate to pass it.

But I do know this: This debate has gone on for nearly 4 years now. This is an iteration of an iteration of an iteration. It is a compromise after a compromise after a compromise. It is a bipartisan bill brought to the Senate Chamber to say: Let us provide patient protections against those HMOs that want to withhold needed treatments for patients. Let's change the odds.

Let me hasten to say, not all insurance companies or HMOs are bad actors. Many of them are wonderful, and do a great job, and serve their patients very well. I commend them.

There are some, however, who look at a patient in the context of profit and loss. A woman in the State of Georgia suffered a very severe head injury. She was put in an ambulance, and on the way to a hospital—she was not quite unconscious—she had the presence of mind to tell the ambulance driver: I want to go to the following hospital. And it was the farthest hospital away, about another 10 minutes. They took her there, but they later asked her why, with a brain injury, she would want to take the extra 10 minutes to go to a further hospital. She said: I know about the hospital that was closer. It is a hospital with a reputation for taking a look at a patient who is coming in and seeing the dollars and cents, the profit and loss. I didn't want my medical care to be the function of someone else's calculation of profit and loss.

This is from a woman in an ambulance with a brain injury. My point is very simple. This country needs to have some basic protections for patients, and the patients want those protections. Especially with the growth of managed care organizations, many of whom do a fine job, but some of whom do not, we need these protections.

We need to say, as a matter of public policy in this country, patients have certain rights. Yes, you have a right to know all of your options for medical treatment, not just the cheapest one the managed care organization might want to tell you about.

Yes, you have a right to an emergency room when you have an emergency. Yes, you have a right to be able to see the specialist you need when you need to see one. Yes, you have a right, if your spouse is being treated for breast cancer and you have changed jobs, for your wife to see that same oncologist who has been working with for her for the last 5 years to fight her breast cancer. You ought to have that right, and this legislation will give you that right.

We will have Senators who will assert that this is a bill about trying to create more lawsuits. It is not that at all. It is about trying to provide patient protections. As I said when I started, the managed care organizations have all the lawyers they need. They can hire all the lawyers they need and want unimpeded. No one is going to come to the Chamber from the other side and talk about limiting the rights

of the big managed care organizations or insurers to hire lawyers, are they? I don't think so. But they will say: We don't want patients to have access to attorneys to hold managed care organizations accountable.

This is all about accountability. The Red Cross can be held accountable. Boy Scouts can be held accountable. Everybody can be held accountable except, in these circumstances, managed care organizations. This piece of legislation says everybody ought to be held accountable.

This is not about lawyers, this is about getting the right care to patients when they need it.

I suspect we will debate this for a couple of weeks. We have had this debate before. This legislation has changed from that time. For example, we hear from small businesses, who are now getting mailings around the country, saying: If Congress passes this Patients' Bill of Rights, this is going to break our small businesses because we will be held accountable. That is not true. In fact, this has changed so that we use exactly the same language the majority party used in its substitute in 1999. This bill isn't in any way putting in jeopardy small businesses. We don't hold them accountable. They are not accountable at all in circumstances where they have not had direct participation in making decisions about patient care. They are not accountable in that circumstance and should not be accountable because they were not making the decision.

This is about managed care organizations and patients and the relationship between the two and the rights patients ought to have.

I have other pictures. I have other stories. I will at some point later describe more of them in terms of what is "medically necessary" because by deciding what is medically necessary is another very important way in which HMOs can withhold treatment.

I am going to show a poster on the issue of medical necessity that is a little more subtle than perhaps the other one I used but just as important. Brenna Nay was born in 1987. She has abnormal facial features characteristic of what is called Hajdu-Cheney syndrome. The shape of her skull is distorted. She had no chin. The question is, is it medically necessary to treat this young lady?

Let me show the result after surgery. They built this young woman a chin. After surgery, does that improve that young woman's life? Is this something you ought to expect would be covered in a health plan? In my judgment, it should.

I have other pictures that are similar. I will use them later.

This "medically necessary" issue is critically important. I feel passionate about these health care issues. I have lost a member of my family. I have sat in intensive care day after day after day and know what it is like to lose a member of my family in a cir-

cumstance I can hardly begin to describe. In my case, my loss didn't have anything to do with the managed care organization withholding treatment. But I understand the passion of parents. I understand the passion of people who are fighting for their lives, who are struggling and fighting mightily against dread diseases and illnesses they know can kill them and then discover they not only have to waste the emotional energy to wage war against cancer or heart disease or so many other problems, but they also have to try at the same time to fight a managed care organization that ought to be covering that which is in their health care plan.

That is not right. That is not fair. These are the types of problems this piece of legislation is designed to try to address. If we can pass this legislation, the country will be a significant step ahead in dealing with patients' needs and protections.

Mr. President, I yield the floor and suggest the absence of a quorum.

The PRESIDENT pro tempore. The clerk will call the roll.

The bill clerk proceeded to call the roll.

(Mr. DORGAN assumed the chair.)

Mr. REID. Mr. President, I ask unanimous consent that the order for the quorum call be rescinded.

The PRESIDING OFFICER (Mr. DAYTON). Without objection, it is so ordered.

#### THE VERY BAD DEBT BOXSCORE

Mr. HELMS. Mr. President, at the close of business Friday, June 15, 2001, the Federal debt stood at \$5,632,910,105,449.16, five trillion, six hundred thirty-two billion, nine hundred ten million, one hundred five thousand, four hundred forty-nine dollars and sixteen cents.

One year ago, June 15, 2000, the Federal debt stood at \$5,644,607,000,000, five trillion, six hundred forty-four billion, six hundred seven million.

Twenty-five years ago, June 15, 1976, the Federal debt stood at \$612,128,000,000, six hundred twelve billion, one hundred twenty-eight million, which reflects a debt increase of more than \$5 trillion, \$5,020,782,105,449.16, five trillion, twenty billion, seven hundred eighty-two million, one hundred five thousand, four hundred forty-nine dollars and sixteen cents during the past 25 years.

#### ADDITIONAL STATEMENTS

HONORING COLONEL JAMES GARRARD JONES, FIRST MAYOR OF EVANSVILLE

• Mr. LUGAR. Mr. President, I rise today to honor a true pioneer in public service, Colonel James Garrard Jones.

Colonel Jones was born in Paris, KY on July 3, 1814, but soon became a resident of the great State of Indiana when