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WOMEN'S HEALTH AND CANCER RIGHTS ACT OF 1997

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH CARE

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDRED FIFTH CONGRESS

FIRST SESSION

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WOMEN'S HEALTH AND CANCER RIGHTS ACT OF 1997

WEDNESDAY, NOVEMBER 5, 1997

U.S. SENATE,
SUBCOMMITTEE ON HEALTH CARE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 2:08 p.m., in room SD-215, Dirksen Senate Office Building, Hon. Phil Gramm, (chairman of the subcommittee) presiding.

Also present: Senators D'Amato, Rockefeller, and Bryan.

OPENING STATEMENT OF HON. PHIL GRAMM, A U.S. SENATOR FROM TEXAS, CHAIRMAN, SUBCOMMITTEE ON HEALTH CARE

Senator GRAMM. If we could have everybody take their seats. We are waiting on several of our witnesses, but we have Senator Feinstein here and I know she is a very busy lady. So what I thought I would do, in the interest of time, is I would let Dianne go ahead and make her statement. Then if our other witnesses are still not here—I see Senator Snowe as well.

So I will let Senator Feinstein and Senator Snowe make their statements. If our other House and Senate colleagues who are testifying are not here, I will then try to make a very brief opening statement. Then when they come we will have them testify, then we will have our panel.

Let me say that I am very honored to have two of our most distinguished and most loved members of the Senate before us today, and I look forward to hearing what both of you have to say.

Senator Feinstein?

STATEMENT OF HON. DIANNE FEINSTEIN, A U.S. SENATOR FROM THE STATE OF CALIFORNIA

Senator FEINSTEIN. Thank you very much, Mr. Chairman. Maybe we should leave while we are ahead. But, nonetheless, I, for one, very much appreciate being here with Senator Snowe, Senator D'Amato, and the others who will testify in favor of this bill.

I know that you have some concerns about these matters, but I would really urge you to take a good look at this because I think what is happening out there increasingly is wrong and does deserve regulation.

Let me just begin by saying this, Mr. Chairman. My father was a general surgeon. My husband, Burt Feinstein, to whom I was married for a long time before he passed away, was a neurosurgeon.

So most of my life I have lived in a family with a surgeon. They always set the length of hospital stay. My father, particularly, was professor of surgery at the University of California Medical Center and headed the department at one point, and really, I think, understood that general anesthesia has a different impact on individuals, removal of a limb has a different impact on individuals, and you cannot be predictive, necessarily, on what the stay should be. There can be many things that happen that determine morbidity, let alone mortality.

The bill that we are proposing today, the Women's Health and Cancer Rights Act of 1997, does just four simple things. The first, is it requires insurance plans to cover the length of hospital stay in the area of mastectomy as decided by the physician, in consultation with the individual patient. It does not set a prescribed fixed number of days or a minimum, it says that this is quite properly the decision of the physician.

To my knowledge, this is the position of the American medical community. This is a decision that should be made by a doctor, not by a pencil-pusher in an insurance company.

Second, it requires health insurance plans to cover breast reconstruction following mastectomy. Insurance plans say, Mr. Chairman, that this is cosmetic surgery. Well, you are never going to lose a breast. My mother-in-law lost her life from breast cancer. My husband's father died of breast cancer. I have a multitude of friends who have.

One of the things that I have seen in the recovery is the ability, through reconstructive surgery, for an individual to feel normal again, not to feel mutilated. As such, it becomes a very important part of the overall treatment for some. Not for all; some people do not feel this way. I strongly believe it should be covered.

It also prohibits the insurance company from financially penalizing a physician for providing medically necessary care or for referring a patient for a second opinion.

If you or I were to go to a doctor, have our annual check-up, and find out we had cancer that could be life-threatening, many of us would want to have a second opinion; what are my alternatives, what are my choices, what are the treatment options? Different physicians will say different things, and a second opinion, when it is life threatening, I do not think is too much to ask.

It prohibits insurance plans from financially penalizing or rewarding a physician for providing medically necessary care for a patient or referring that patient. Many insurance companies, believe it or not, today give incentives not to do so. I think that is improper for the medical profession to have to practice that way.

Now, there were two cases that came to my attention in California. I received a letter last November from a woman by the name of Nancy Kushoe. She is just about my age. She lives in Northern California in Newark. She had a modified radical mastectomy on November the 4th at 11:30. She was pushed out at 4:30 that afternoon.

She tells me, she could not walk and the hospital staff would not help her walk to the bathroom. She says, "Any woman under these circumstances should be able to opt for an overnight stay to receive professional help and strong pain relief, let alone recover from an anesthetic."

Victoria Burke of Los Angeles wrote that she had a mastectomy and lymph node removal at 7:30 a.m. on November 13th that same year and was released from the hospital seven hours later, at 2:30 in the afternoon. She was given instructions on how to empty two drains attached to her body, and sent home. She concludes, "No civilized country in the world has mastectomy as an out-patient procedure."

Mr. Chairman, I, myself, have had two surgeries. Fortunately, they were non-malignant tumors that I had in my breasts. The second one was for removal of two tumors. I remember, I had two drains. I remember the impact of the anesthesia. I could not have left the hospital without an overnight stay, physically could not have done it. I had 3 days in the hospital, and my tumors were not malignant.

Therefore, someone with a malignant tumor, having a major amputation, having a major anesthetic at 7:30 in the morning, and then at 2:30 in the afternoon being told, that is it, here is what you do when you get home, if you can do it, go home.

So I think there is a need for the bill. I will put my statement in the record and allow my colleagues to speak. But, as I say, I know you have reservations. This bill is simple, it is straightforward, and you know what? If we pass it, it is going to work.

[The prepared statement of Senator Feinstein appears in the appendix.]

Senator GRAMM. Thank you, Dianne.

Olympia?

STATEMENT OF HON. OLYMPIA J. SNOWE, A U.S. SENATOR FROM THE STATE OF MAINE

Senator SNOWE. Thank you, Mr. Chairman. Mr. Chairman, I want to applaud you for convening this hearing on such an important issue to so many women in America and their families. I want to commend Senator D'Amato, Senator Feinstein, both of my colleagues who have been leaders on this issue, and for drafting this very important legislation.

This bill, as Senator Feinstein indicated, is doing what is right and what is best for women in America who have a diagnosis of breast cancer and face the potential of a mastectomy.

The reason for this legislation is simply because so many women have been denied the best medical care when it comes to this issue, and that is unacceptable in a country that has tremendous medical resources. We certainly can do better.

We are all familiar with the statistics, but they are certainly worth repeating: 180,000 women are diagnosed with breast cancer every year in America; 73,000 in 1992 statistics indicated that they underwent mastectomies, another 30,000 had breast reconstructive surgery.

What this legislation is designed to do is to provide crucial protections at a time when the health care market is facing tremendous competition, not to mention the pressure of reducing prices.

We want to be sure that doctors are not pressured by health insurance plans to release prematurely mastectomy patients before it is medically appropriate. We know that there have been health insurers who have provided guidelines recommending that mastectomies be done on an outpatient basis.

In fact, there was a New York Times article that was published earlier this year that indicated that eight percent of mastectomies were done on an outpatient basis. Many, many doctors in the medical community have indicated that it does require a much longer stay. In the State of New York alone, they have 3.6 days, on average.

What we are attempting to do with this legislation is to restore the medical decisions to where they rightfully belong, and that is with the physician and the patient. The physical scars that are left by a mastectomy are very difficult, require supervision. We have heard of stories where there have been a tremendous amount of complications without that supervision at home, not to mention the psychological trauma as a result of a mastectomy.

As Senator Feinstein indicated, this legislation also includes breast reconstructive surgery coverage as well. In my State we have such a law. But it is interesting, what happened to one of my constituents by the name of Bonnie Bishop. She thought that she had such coverage, but discovered that her employer had health insurance, but was self-insured.

Well, State laws do not cover self-insured plans, so she was denied breast reconstructive surgery reimbursement under her policy because it was not medically necessary.

Well, we think that there clearly is a double standard when 43 percent of breast cancer survivors are denied coverage on this basis when, in fact, there is coverage in health insurance plans for surgery that is done to other parts of the body affected by cancer.

We think it is appropriate. It is not surgery that should be deemed to be cosmetic, but rather restoring wholeness to a woman. We want to allow breast cancer survivors to move ahead with their lives, and breast reconstructive surgery allows them to do that. So, this legislation would remove that double standard.

Finally, this legislation includes a provision to provide for coverage of a second opinion with a specialist for an individual who has been diagnosed with cancer, again, empowering individuals to be proactive in their medical decisions, to have the most informed, up-to-date information, the best information, so that they can make a very difficult decision. It can be a decision based on life or death.

Certainly we want to make sure that people are spared from senseless and needless surgery, or even death, because of a false diagnosis. So this will help individuals to make the best and most informed decision.

Mr. Chairman, I thank you for this opportunity to testify, and members of the committee, because I would hope that we would be in a position at some point in this Congress to move this legislation.

It is certainly, I think, something that Americans deserve to have action taken on when it comes to these very critical issues, and it is also important to give voice to these issues and to send a message, I think, to insurers that we need to make the best appropriate medical decisions and not just having a bureaucrat's bottom line. Thank you.

[The prepared statement of Senator Snowe appears in the appendix.]

Senator GRAMM. Thank you.

Let me now recognize Al D'Amato, who is a member of this subcommittee, and who is the leader on this issue.

Senator D'Amato?

OPENING STATEMENT OF HON. ALFONSE D'AMATO, A U.S. SENATOR FROM THE STATE OF NEW YORK

Senator D'AMATO. Well, thank you very, very much, Mr. Chairman. Again, let me thank you for holding this hearing, recognizing all of the pressures to come to bear as we move towards an adjournment of this session of the Congress. That is why I thought it was so important that we have this hearing.

I want to commend and thank both my colleagues, Senator Feinstein for her not only being here and testifying, but being here and being in the forefront on many occasions involving this legislation; Senator Snowe for her strong support and, indeed, setting a very impressive mark for us to follow in terms of many of the important underlying provisions in this bill.

This bill happens to be, I think, a basic minimum standard that we need. I am going to ask that the full text of my remarks be included in the record, Mr. Chairman, as if read in its entirety.

Senator GRAMM. It certainly will be.

[The prepared statement of Senator D'Amato appears in the appendix.]

Senator D'AMATO. This nonsense, this business, this charade, that we should not legislate by body part, but then if we try more comprehensive legislation the whole world comes saying, we do not need this, that, or the other thing. This is minimum. And we are going to vote on this and it may or may not come out of this committee, but I can tell you, forget about campaign finance reform. I mean, people say you are going to get a vote on that.

The first piece of legislation that moves through that I can put this on, I promise you, I will do it. If people want to filibuster it, they will have to kill that bill. But we are going to get a vote on this. I have been trying now, with my colleagues, for 1 year to get this thing acted on. Now, what is it? It is common sense.

We are going to hear the insurance carriers say, we do not have any need for this. We do not do these things. Well, if you do not do them, then why are you opposed to it, if you do not put people out on the street within 24 or 48 hours or when they should not be, maybe it is 5 days or 7 days? If you have a person who has had an operation, and generally that operation results in the person being discharged within 24 hours, but in this particular case it is 10 days.

You mean to tell me the insurance carrier should say, put a person who is sick out on the street or send them home where they have nobody to take care of them? That is a special bond, a bond that really exists between the patient and the doctor, not a member of Congress, not a bean counter who is worried about saving money for an insurance carrier. I have never heard of such hokum.

I hear colleagues, respected colleagues, telling me, oh, I would like to support it, Senator, but after all, I do not want to legislate by body part. If it was somebody that he loved and he cared about, maybe he would think a little differently.

Maybe when some of our members hear about second opinions, I would like to know if any one of us had a loved one, God forbid, who was diagnosed with cancer, if we would not want to get a second opinion as to how to treat them. You are darn right, we would.

So does that mean a working person who does not have the money, they are not going to be able to do it because their insurance carrier says, no, one; that is it, you take it or leave it? I mean, do you think I feel strongly? You are darn right I do.

I have seen, tragically, the results of breast cancer in particular strike friends and loved ones. A young girl with triplets, 37 years old, fighting for her life. Fighting for her life. This is real. I have to tell you that this is minimum. This is minimum, what we ask for.

Bean counters should not be threatening to hold money from a doctor because he may prescribe a treatment that somebody says, that costs more than another treatment. That is up to the doctor to make that determination. Cosmetic surgery. You are going to hear, Mr. Chairman, from a woman.

The reason that this provision is in there is because when Senator Feinstein and myself and Senator Snowe initially drafted our legislation and we sent it out for comments, I was contacted by Mary McCarthy, executive director of the American College of Obstetricians and Gynecologists of New York. She contacted us in her professional capacity, but also then related what took place to her—she is a breast cancer survivor—and how they attempted to deny her reconstructive surgery. It is wrong. That is going on.

So if, indeed, there are two or three people who are going to say, well, our company does not do that, that is fine. Maybe your company does not do it. But we want to see to it that everyone gets these minimum protections.

Last but not least, you know, but I think most do not and the people behind those cameras grinding away who may or may not see this do not understand why it is we need this legislation. The State of New York has passed this identical bill. We drafted it here, we went to the State, they passed it unanimously, Democrats and Republicans, conservatives and liberals. I have not heard of any horrible things taking place. It still seems to me more people are running in to try to meet the need and sell insurance.

But what happens is, fully 40 percent of those people covered by various plans are covered by those who are self-insured. Therefore, notwithstanding, as Senator Snowe has indicated, that we have passed the State law, the unintended consequences of the ERISA preemptions were such that they are not covered. That is what we are trying to do here.

ERISA was never intended to make it impossible for States to provide these basic guarantees, but rather to see to it that States did not endanger the ERISA provisions as it related to retirement that the Federal Government set its broad standards. So this is really an unintended consequence that we are trying to deal with.

Now, Mr. Chairman, I have to tell you, I respect no one more in the Senate than you and your leadership when it comes to guaranteeing and fighting so that Americans can determine for themselves how to best spend their money, how to protect themselves.

I think that this is a bill that falls in the nature that you would and could support. This is a bill that gives people choice. This is a bill that says, yes, when you are diagnosed, you should have an opportunity to get a second opinion, when it comes to life threatening.

By the way, that is for all cancers, not just breast cancer. That is any cancer. We saw that. So to those who say, well, it is just body parts, maybe it is a start. But it is a pretty good start.

It is a pretty good, comprehensive bill and it goes a long way to filling up some of the gaps that have taken place as a result of the necessary push to economize, to save, but never, never should it be at the expense of that special relationship between what the patient needs and what the doctor would ordinarily prescribe and what may or may not be available because of economic interest having little, if anything, to do with the basic health and treatment of that patient.

Again, I thank you for making this time in your very, very busy schedule for us today for this hearing.

Senator GRAMM. Well, thank you, Senator D'Amato. Let me thank you, Senator Feinstein, and thank you, Senator Snowe.

Sue Kelly, a Congressperson from New York, was going to be here, but apparently she had a vote. I know all of you are busy, and I want to thank you very much for coming.

I would like to now call our panel. Gail Wilensky, who is health economist and senior fellow for Project HOPE in Washington, DC. I hope Gail is here. Mary McCarthy, who is executive director of the American College of Obstetricians and Gynecologists of New York State; Lillie Shockney, who is an R.N. and director of Education and Outreach at Johns Hopkins Hospital Breast Center in Baltimore; and Fran Visco, who is president of the National Breast Cancer Coalition in Philadelphia.

I do not think Gail is here. What we will do is go ahead and begin with the three of you, then when Gail comes we will hear from her.

So since you are on the right, Ms. Visco, we will begin with you, first. Let me thank each of you for coming, very much. What I would like to do is agree to put your written statements, if you have one, in the record as if you presented the whole thing. If you could try to limit your summary to 5 minutes or less, it would be very, very beneficial to us.

I have an additional colleague, Senator Bryan, who is here. Before we begin this, let me see if he has an opening statement he wants to make.

OPENING STATEMENT OF HON. RICHARD H. BRYAN, A U.S. SENATOR FROM NEVADA

Senator BRYAN. Let me preface my comments by applauding our colleagues for having introduced this legislation. Every 3 minutes in this country, a woman is diagnosed with breast cancer, every 12 minutes a woman dies, 44,000 in a year. For many women in America, the two most frightening words that they will hear from their physician during the lifetime is breast cancer.

So I believe that what our colleagues have proposed in terms of their objectives, Mr. Chairman, is something that I can identify with in terms of establishing Federal minimal standards in terms of providing reconstructive surgery, second opinions, and also to eliminate any incentives that may be provided in any HMO plans that would be a disincentive for physicians to provide and offer a full range of care for services.

I was particularly taken by the testimony of our colleague Senator Feinstein, who related her own personal circumstances. Earlier this year, Mr. Chairman, I had occasion to be at the White House where this issue was discussed.

A woman who is a staff member of one of our colleagues in the other body described in absolutely moving and gripping detail her own personal experience, how she was forced to leave early, the difficulty that she was having in dealing with the pain and the post-operative effects. No woman should have to confront this type of circumstance.

Earlier this week I received a letter from a young woman in Nevada who had a similar experience. She asked that her name not be used. So I think it is entirely appropriate that we provide legislative minimal standards.

I might just indicate, as you know, Mr. Chairman, a former colleague of ours who took the issue of the drive-through delivery on last session, which I think every member of this committee, I think every member of the United States Senate, supported that legislation, recognizing that there needed to be protection for young mothers who had recently delivered in providing the kind of obstetric and pediatric care that were needed for her and her child.

So again, let me commend you for convening this hearing. I look forward to hearing from our witnesses. I would ask unanimous consent that my full text be made a part of the record, Mr. Chairman.

[The prepared statement of Senator Bryan appears in the appendix.]

Senator GRAMM. Thank you, Senator.

Ms. Visco?

STATEMENT OF FRAN VISCO, PRESIDENT, NATIONAL BREAST CANCER COALITION, PHILADELPHIA, PA

Ms. VISCO. Thank you, Mr. Chairman and members of the Finance Subcommittee on Health Care.

I am Fran Visco. I am a breast cancer survivor, a wife, a mother, a lawyer, and president of the National Breast Cancer Coalition.

Now, the coalition is a grass roots advocacy organization of more than 400 member organizations, and more than 50,000 individuals.

I spend a great deal of my time speaking to women across this country, many of whom have been through the terrible ordeal of hearing they have breast cancer, of mastectomy, of breast reconstruction.

I speak to women every day who are fighting for their lives. It is unfortunate that too many of them also have to fight their insurance companies while they are trying to deal with the incredible issues attached to a life-threatening disease like breast cancer.

Now, as an activist, I am committed to doing my best to ensure access to quality care for all women and for their families. As we examine the issues surrounding quality health care, I know that you keep the issues surrounding breast cancer in perspective. You have heard from Senator Bryan, Senator Feinstein, and many others the statistics surrounding this disease, that there are 1.6 million women living in this country today with breast cancer.

I applaud the Congressional sponsors and supporters of the Women's Health and Cancer Rights Act of 1997, as well as the sponsors and supporters of additional pending legislation addressing these issues.

It is somewhat difficult for me to sit here, as a woman who has had breast cancer, and hear debate over how long someone should stay in the hospital, over whether or not they should have a second opinion. And I want to say that I found Senator D'Amato's argument on the second opinion particularly compelling and I do not think I could add anything to that. I think that we would all would want our loved ones and ourselves to have access to second opinion.

I also understand the argument about Congress not wanting to focus its time and efforts on disease-specific legislation. We prefer that you not have to do that also. Unfortunately, you do because the Nation did not have the courage to enact overall health care reform. Until the day we do, we have to deal with issues that arise. We have to deal with the abuses that arise in the meantime. This happens to be one of them.

I want to briefly speak about the specifics of the legislation. The ability of insurance companies to reduce significantly minimum standards of care for breast cancer patients is a shortcoming that we have to deal with now.

First of all, the length of stay in a hospital after breast cancer treatment must be determined by individual medical needs based on an appropriate level of evidence and not by cost.

I have heard there are many women who do undergo outpatient mastectomies and there are programs in place to help women through that. Those programs are very few and far between; there is not a lot of education. When a woman and her doctor feel it is appropriate for her to have an outpatient mastectomy, then we fully support that.

But what has happened now is the system has been turned on its head. In too many circumstances, what is expected is that a woman will have an outpatient mastectomy. What you have to argue for is a night or two, or more, in the hospital. It should be the other way around.

Breast reconstruction surgery should definitely be covered by insurance after a mastectomy. This is not cosmetic surgery, this is a medical necessity for most women.

In addition to the second opinion, we need legislation that provides for strong consumer protections. They must be included to ensure that a breast cancer patient's interests are not compromised in any way.

You know, it is really important when women are faced with the trauma of breast cancer. I can tell you what you feel like when you get that diagnosis. Your first thought is you are not going to live very long. Your second thought is, you have no control over this disease that is destroying so many aspects of your life.

We cannot afford to put women through this trauma also. If a woman and her doctor feel that it is medically necessary for her to stay in the hospital, then that is what we should be supporting as a Nation and as a country.

Now, I will submit my full testimony for the record and I will agree to your plea that I limit my remarks to 5 minutes. But what I want to leave you with is the incredible importance of this piece of legislation and the support that it has from the constituency across this country, from the women with breast cancer, from their families and friends, from all women who are at risk of this disease, and that is all women.

So I thank you very much for holding this hearing and I want to continue to work with the committee and with Congress in getting this legislation enacted, and also on working on meaningful health care reform so we do not have to be here on disease-specific issues in the future.

Thank you.

[The prepared statement of Ms. Visco appears in the appendix.]

Senator GRAMM. Thank you.

Ms. Shockney?

STATEMENT OF LILLIE SHOCKNEY, R.N., DIRECTOR OF EDUCATION AND OUTREACH, THE JOHNS HOPKINS HOSPITAL BREAST CENTER, BALTIMORE, MD

Ms. SHOCKNEY. Hi. My name is Lillie Shockney. I have been at the Johns Hopkins Hospital for the last 15 years. Most recently for the last 10 I was director of Performance, Improvement, and Utilization Management. Beginning in July, I assumed the role of Education and Outreach director of the Johns Hopkins Breast Center.

I am also a breast cancer survivor. I had a left mastectomy in July 1992, right lumpectomy in July of 1993, and right mastectomy in July of 1994, so I am very familiar with mastectomy surgery at personal and professional level.

I am also vice president and co-founder of an organization called Mothers Supporting Daughters With Breast Cancer, and am very active as a volunteer with numerous breast cancer organizations.

Since 1994, I have been doing a lot of traveling across the country speaking about breast cancer. Just in the last 6 weeks, I have traveled to 21 different cities. As I have traveled from State to State, I have been exposed to a lot of women who are breast cancer survivors who have shared with me candidly their personal stories related to their treatment. These stories have confirmed for me that we have a wide variation in the quality of care that women are receiving who are battling this disease.

There have been some hospitals and doctors, as has been described to me by patients, who are actually still providing surgical care the way that we did 30 years ago for mastectomy surgery.

There are other hospitals and doctors that I have also had an opportunity to talk with their patients who have taken a more innovative approach and seriously wanted to work hard on improving patient care and empowering women to participate in the decision making about their care so that their surgery is less traumatic.

Though I believe that this bill under consideration today is a dramatic improvement over the bills previously considered that recommended a specific length of stay for mastectomy surgery and for lymph node dissection, I am concerned that it does not solve the real medical dilemma that women facing breast cancer have today.

We need to be striving to improve patient care for patients undergoing breast cancer surgery rather than unknowingly promote keeping what I believe will be status quo care. The wide variations in the patients' personal stories reaffirmed this for me, that the time has come for us to address what is the real issue, and I believe that that is what it is.

Women should be able to feel confident that they are receiving the best care that they can get, no matter where they go in seeking that care. There are variations in the degree in which the patient is empowered with information.

We need to be promoting the development of a comprehensive patient education program and have teams of health care professionals dedicated to striving to improve care and treatment provided to women battling breast cancer. The bill does not seem to address this particular need, which I think is important.

We will, therefore, see patients staying in the hospital 1 day, and another patient with the exact same procedure staying in the hospital 10 days. I think, in essence, what we are doing is that we have failed to define what is best care.

In order for women to be able to participate in the decisions about their length of stay, they need to be educated about their disease, treatment options, and directly participate in the decisions about their care as an active partner on their health care team.

This bill does not enforce the need for patient education and, as a result, patients may choose to stay in the hospital for an extended period of time because they lack that knowledge that that may not be in their best interests medically.

One risk of extended hospital stays is exposure to germs while you are in the hospital. Patients who have drains in place have a higher incidence of probability of developing an infection while hospitalized than those who do not.

The tendency may be for the patient and the doctor to jointly decide together that the patient could stay in the hospital until her drains are removed. On average, that is between 10 and 12 days. I do not think that this, as a result, would actually imply that we are improving care.

It could also discourage health care professionals from taking the time to develop and incorporate as part of their patient's care a comprehensive patient education program that empowers the patient to make good decisions, when assisted by her health care team.

Last year at this time there was considerable discussion in the media and in committee sessions like this about mandating that managed care pay for at least a 48-hour stay for mastectomy, and 24-hour stay for women having lymph node dissection.

I expressed my concerns last year regarding that particular bill that was presented in Maryland because I feared that it would discourage hospitals and health care professionals involved with breast cancer patients from taking the initiative to improve patient care, in essence, work to eliminate the occurrence of nausea and vomiting rather than consider it to be what is expected.

I recognize that this bill under consideration today is different than those that have been presented before. Rather than mandating a specific length of stay for hospitalization, it will be left up to the doctor and the patient. I very much think that that is a good idea.

Though at first blush that does sound like the way to go, when I thought more about it, in the long run I do not think that we would be doing justice to women who follow in my footsteps and are battling this disease.

This is because such a bill will actually discourage health care professionals from developing improvements in surgical management that women deserve. We run a risk of women continuing to be hospitalized for several days due to nausea and vomiting and due to pain, when we know that now there are treatment plans available, one of which is at Hopkins which I take great pride in. We have been able to eliminate the occurrence of those things.

Senator GRAMM. Go ahead and finish your statement.

Ms. SHOCKNEY. One of the things that I think that we therefore need to address, is to take a look at, what is best care, and be promoting the development of that.

Hopkins approached Milliman & Robertson, the developers of the criteria that insurance companies have been using, and said that it was better care, what they termed "ideal care," to be doing ambulatory surgery mastectomy, but it was not based on any real clinical studies. I would like to see clinical studies done.

We approached Milliman & Robertson last year and asked them if they would undertake such a study and fund it, and they said they would strongly consider it. Last week we got word that they have changed their mind, because they no longer think length of stay with mastectomy is an issue, which I thought was fascinating.

So what I would like you to do is consider rethinking this portion of the bill, because I am not sure that it is going to mean better care for our patients. I fear that it may instead take us backwards and we will discourage encouraging patients to participate in decision making, empowering them with enough information so that they can make good medical decisions on behalf of themselves, and work, instead, to improve care across the Nation.

Thank you.

[The prepared statement of Ms. Shockney appears in the appendix.]

Senator GRAMM. Thank you very much.

Ms. McCarthy?

STATEMENT OF MARY ARMAO McCARTHY, EXECUTIVE DIRECTOR, THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS OF NEW YORK STATE, ALBANY, NY

Ms. MCCARTHY. Good afternoon. I am testifying today as an individual and as a health care advocate. My name is Mary Armao McCarthy and I am the executive director of the New York State Office of the American College of Obstetricians and Gynecologists.

Unfortunately, working on health care issues does not stop you from getting the diseases, and I am a breast cancer patient myself. I have had personal experience with three main areas in the legislation: with mastectomy, reconstructive surgery, and second opinion.

Because of my work, I am well-informed on health care systems. I believed I had excellent health insurance. Yet, my own reconstructive surgery and my second opinion were denied by my health care plan.

My reconstructive surgery was denied in April of 1996 as not medically necessary. My plastic surgeon and I worked very hard through traditional channels in my health care plan and we could not have my surgery approved. It was only through the intercession of colleagues in the New York State legislature that my health insurance plan reversed their decision and approved my surgery.

I would like to take a moment to explain to you why reconstructive surgery is important for a woman who chooses it. My cancer required a mastectomy and my mastectomy was clinically curative, but my reconstructive surgery was emotionally healing.

There is no longer a reminder every day of my cancer. There is no longer a reminder when I dress in the morning, in intimate moments with my husband, or if I am relaxing at home in a nightgown and bathrobe with my children. I can look and I can feel normal.

Unfortunately, the denials for breast reconstruction are serious and they are rising. In a 1996 study by the American Society of Plastic and Reconstructive Surgeons, 84 percent of plastic surgeons reported that in the previous year they had had over 10 denials for breast reconstruction for cancer patients.

For a disease of the magnitude of cancer, it is vital to have access to a second opinion and to be able to go outside your HMO, if necessary, for special expertise. To my own surprise and to the surprise of the physicians in my plan, my HMO adamantly refused to authorize my second opinion. I had a second opinion because I paid for it myself.

During the high physical and emotional stress of cancer diagnosis and treatment, access to second opinion must be a routine, required insurance benefit.

In the interest of time, I thought I would put aside my comments on mastectomy, they are in my written text, and defer to the others. But I would be happy to answer questions on this subject.

I would point out that I feel it is alarming that figures show that between 1991 and 1995, outpatient mastectomies have increased from 1.6 percent to 7.6 percent, and that an appropriate length of stay has to be protected.

In conclusion, I am very pleased to report that the provisions contained in the Women's Health and Cancer Rights Act are now law in New York State. I applaud the leadership of Senator Al D'Amato and the work of the New York State legislature and Governor George Pataki in this accomplishment.

Regrettably, however, it is estimated that over half of women in New York State are not protected because of the ERISA exemption. The Federal legislation is needed to close that gap and to ensure that women across the Nation have these benefits.

The American College of Obstetricians and Gynecologists endorses the Women's Health and Cancer Rights Act.

The success in New York was due to strong bipartisan support. I am very pleased to see that that kind of bipartisan effort is already under way on the national level.

I look forward to being in Washington next year and to having seen this measure passed by Congress.

Thank you.

[The prepared statement of Ms. McCarthy appears in the appendix.]

Senator GRAMM. Thank you, Ms. McCarthy.

It is now my great pleasure to introduce Gail Wilensky. We all know Gail. She is one of the most thoughtful people on health care issues in the country, and we are very proud to have her here.

Thank you, Gail.

STATEMENT OF HON. GAIL R. WILENSKY, PH.D., HEALTH ECONOMIST AND SENIOR FELLOW, PROJECT HOPE, WASHINGTON, DC

Dr. WILENSKY. Thank you, Mr. Chairman.

Mr. Rockefeller, I hope you are recovering well from your own encounter with the medical system.

As you have indicated, my name is Gail Wilensky. I am a John M. Olin Senior Fellow at Project HOPE. I am also, as you know, the chair of the newly-appointed Medicare Payment Advisory Commission, and a former Administrator of the Health Care Financing Administration.

I am here today, however, as somebody who brings some expertise in health care policy and financing, and the views I am expressing are my own and not any of my affiliated institutions.

Breast cancer and breast cancer surgery are clearly deeply emotional issues. Of the group at the table, I am the only one who has not been afflicted by this disease. It is easy to understand the sympathy that the issue raises. However, it is not clear to me, and I will try to share with you some data to support this, that there is a problem requiring breast cancer coverage, that requires the new legislation, and, furthermore, the proposing new Federal mandates on private health insurance coverage raises a series of concerns, concerns about the role of the Federal Government in areas traditionally covered by the States, concerns about the impact of mandates on the cost of health care, and the impact of mandates on locking in standards of care that exist at a given point in time.

As I know all of you know, there was an article about a year ago in the Hartford Courant followed up with some articles in the Washington Post and The Wall Street Journal, suggesting that two Connecticut HMOs were requiring physicians to perform some mastectomies on an outpatient basis.

Charges were led that, because of the changing nature of health care plans, there were limits of coverage for mastectomy to outpatient treatment, and in other ways that insurance was negatively affecting the treatment of cancer surgery.

While the empirical evidence that exists suggests that the rate of outpatient mastectomy remains relatively small—it has been growing somewhat, as has been indicated—but it also suggests that the rates actually between HMOs, other forms of managed care, and fee-for-service are quite comparable. At least, they are not higher for managed care.

This is based on some studies that have been done in the State of New York, indicating, if anything, some of the more traditional plans, including more traditional Medicare. We are using more outpatient surgery than, in fact, the HMOs or managed care.

It also appears that this is the case in the private sector. There are some differences. The differences are not small. As has been pointed out, in fact, the vast majority of mastectomies continue to occur inpatient, although according to the article and earlier testimony of Ms. Shockney, there are instances suggesting that that may perhaps not be, in fact, the best medical care that can be provided to women under some circumstances and with certain support conditions at home.

Aside from the philosophical issue about the role of government, there are some undesirable and unintended consequences of increasing Federal mandates. One has to do with the cost of health care. This is an issue that we heard a lot about several years ago when health care reform was being discussed.

There have been a variety of estimates as to how much the mandates can increase coverage cost, some 12 percent in Virginia, some 22 percent in claims costs in Maryland. It has been a sufficient problem that, in some States, there has been an attempt now to allow States to override their own mandates in order to offer health insurance coverage to uninsured employed individuals in an effort to try to get them insurance coverage.

There is also a problem, although it is not necessarily linked to the legislation, that government-established mandates tend to lock in whatever standard of care exists at a certain point in time.

What it means, is that what may be common practice in one period—in this case, inpatient care for mastectomy—tends to become a requirement in another period, particularly from the patient's point of view, if not from the physician's point of view. There becomes a sense of entitlement to a service, even though it will require a physician's certification.

Any doubt about how that can happen, one should only look to the health care expenditures for home care in Medicare, where we have seen a real explosion in costs, in part because it is very difficult for the physicians to say no to these families.

Mandated benefits laws, as I have said, do not prohibit medical progress directly, but they can impede the progress that has been occurring in the medical community in order to find ways to deliver care, new and better ways, and to some of the changes that have been going on outside the medical community in the marketplace to try to find cheaper ways to deliver care as well.

As I have said, I was impressed with the information that was in Ms. Shockney's testimony about the number of instances where it is shown that, in fact, women who have had outpatient mastectomies, given the kind of support that they need, have, in fact, had lower infection rates and higher satisfaction. But I will leave that decision where it belongs, with the medical professionals.

Let me make a couple of concluding comments. It is only in the last decade that we have really started to focus attention on the need for more information on clinical effectiveness and outcomes. We know there are wide variations in medical practices, even after we adjust for patient characteristics. This is in breast cancer surgery as well.

The Federal Government, in my opinion, clearly has a role in funding research in these areas and in helping to disseminate the information to clinicians and patients alike. Some of this now goes on in the NIH, in AHCPR, and other parts of HHS, but more can, and should, be done.

Patients also need to understand that physicians, hospitals, and health care differ in terms of the quality of medical care and the satisfaction that they are serving, and seeking out information will help them put important pressure on the health care system.

If I may, one final point as well.

Senator GRAMM. Sure.

Dr. WILENSKY. Many of the problems frustrating consumers most about their health insurance coverage would disappear if we would allow consumers to have a more active role in choosing their health insurance.

Most of us have health insurance that comes through our employers because of the tax subsidy associated with employer-sponsored insurance. Some of us have choices, particularly those working for the Federal Government, the State of California, and large employers, but many of us do not have much choice.

The Kassebaum-Kennedy legislation, the Health Insurance Portability Act, passed in the 104th Congress allows self-employed and sole proprietors to deduct the premiums they pay for insurance, thus opening up the tax subsidy to this group who had previously been denied a tax subsidy and a lot of choice.

There was a provision in the Dole-Packwood legislation that was proposed in the 104th Congress that allowed small employers to buy into the Federal Employee Health Care Plan on a non-subsidized basis, thus potentially opening up a wide range of choice to employees of small firms.

Expanding the ways in which employees can make use of the existing tax subsidy from employer-sponsored insurance would allow patients and families to exert far greater control over the kind of insurance they purchase and drive the health care system to be more responsive to their desires. The Congress has taken some steps in this direction. I urge you to take more.

Thank you.

[The prepared statement of Dr. Wilensky appears in the appendix.]

Senator GRAMM. Thank you very much, Gail.

Senator Rockefeller, do you want to make an opening statement?

Senator ROCKEFELLER. No. Over the course of questioning, Mr. Chairman, I will add some comments.

Senator GRAMM. I am going to save my comments and questions until last. Excuse me. Congressman Kelly, I think, has come in. If she is here, let me call her up to the witness table. Congressman Kelly is the leader of this effort in the House, and she was not here with our previous panel since she had to vote on the House. We all understand that problem.

Congressman Kelly, let me thank you for joining us. We will, of course, print your entire statement in the record. What I would like to do, since I know you are busy, is to have you go ahead and make your statement, and then we will let you go back to work on behalf of your district in New York, and then we will go ahead and proceed with our questions to the panel.

Congresswoman Kelly?

STATEMENT OF HON. SUE W. KELLY, A U.S. REPRESENTATIVE FROM THE STATE OF NEW YORK

Congresswoman Kelly. Thank you very much, Mr. Chairman, Senator Rockefeller and other members of the subcommittee.

I am Congresswoman Sue Kelly and I am the primary sponsor of the House companion bill to S. 249. I thank you for having me here today, but more importantly, thank you for holding the hearing on this legislation because it is of paramount importance to the 2.6 million women living with breast cancer. I also want to thank Senators D'Amato, Feinstein, and Snowe for leading the way with this legislation.

In many families, every month is breast cancer awareness month because sometimes their mother is fighting the disease, sometimes because an aunt is in remission, sometimes because a grandmother just lost her life to breast cancer, or in my case because my sister is fighting this silent predator.

This cancer touches more than 180,000 women each year. Since you have already heard testimony outlining the provisions of the Women's Health and Cancer Rights Act, I would like to focus on the need for this legislation as well as respond to a few of the main criticisms of the bill.

I have heard some of our opponents claim that the bill is unnecessary because there is no problem of drive-through mastectomies, that coverage of reconstructive surgery is not really being denied, and that there are very few incorrect cancer diagnoses.

If that were the case, then we would have no stories of women being released from hospitals as early as six hours after a mastectomy with instructions on emptying drains attached to their bodies. But we do have these stories, horrible stories.

It is important to clarify that the Women's Health and Cancer Rights Act sets no arbitrary limit on a patient's length of stay. This legislation merely places that decision where it belongs, with the physician and the patient. The point is, a doctor should make this decision in consultation with the patient, not an insurance company bureaucrat.

I would like to share with you the experiences of one of my constituents, Mrs. Jeannette Spada, of Woppinger's Falls, New York, who was diagnosed with breast cancer in 1985 at the age of 37. Since that time, she has had two mastectomies and was initially denied reconstructive surgery on the basis that her health care policy deemed the procedure cosmetic.

Just last month she wrote the following: "I did not realize there was a dollar limit on my physical and mental well-being. The powers that be at these HMOs have to be made to realize that there are living, breathing people attached to their paperwork, and we would like to remain living and breathing."

Studies have documented the fear of losing a breast, and the consequent person cost of reconstruction are leading reasons why women do not participate in early breast cancer detection programs. We could ease such fears by providing coverage of breast reconstruction.

This bill also covers second opinions for all cancer diagnoses. Up to one-fourth of all invasive breast cancers are not detected by mammography in 40- to 49-year-olds. It is unacceptable that we abandon patients unknowingly in need simply because of a false negative test when a second opinion could save their life. If people are worried, they ought to be able to have a second opinion.

The experiences of the thousands of breast cancer survivors, including my own sister, have made me realize that we should have no greater priority than empowering those with breast cancer with the right and ability to play an active role in the management of their treatment.

It is our obligation as leaders to ensure them that their medical treatment is in the hand of physicians, not insurance companies. It is a profound injustice when health care forgets about the patient. Yet, with regard to mastectomy recovery and breast reconstruction following a mastectomy, this is what has been going on.

I realize that some members of Congress, as well as a few interest groups, are opposed to the Women's Health and Cancer Rights Act, typifying certain provisions of the bill as mandates leading to government-controlled health care.

Developing a system of health care which maximizes an individual's control over one's health care is a goal I strongly support. Furthermore, I agree that free market principles could ensure that the health care we receive is the highest of quality. However, while this is certainly a worthy goal, we are definitely not there yet.

Well, meanwhile, how can we in Congress turn our backs on those asking for the mere right to make their own care decisions with their doctor? Currently, HMO more appropriately stands for Healthy Members Only.

Most Americans do not have access to multiple health care plans or program options from which to choose. Until they have this choice, it is going to be necessary at times for Congress to enact targeted reforms such as this bill.

This bill will safeguard quality care, while at the same time avoiding overly broad regulations and mandates. Let us face it. If the one-size-fits-all mentality does not work for government-controlled health care, why should it work for the managed care organizations?

Mr. Chairman, how many breast cancer casualties are we willing to witness in our movement to market-based health care? Approximately 44,000 women in the United States will die of breast cancer this year alone. That is only 4,000 less than all of the American men and women killed in battle during the Viet Nam war.

The Women's Health and Cancer Rights Act aims to give women with breast cancer the opportunity to participate in the management of their treatment and the dignity to endure the fight. Please let us empower these women.

I thank you for letting me testify before you.

[The prepared statement of Congresswoman Kelly appears in the appendix.]

Senator GRAMM. Thank you very much, Congresswoman Kelly. It was very persuasive testimony.

Congresswoman Kelly. Senator Gramm, I do not mean to interrupt, but I want to point out one thing. From the American Cancer Society figures, in your district the estimated breast cancer mortality in 1997 is 2,800. The estimated new breast cancer cases in 1997 will be 11,500. Mr. Rockefeller, in your district, I can give you those figures, too.

Senator ROCKEFELLER. Congresswoman Kelly——

Congresswoman Kelly. I think it is important you realize, these are women that really count on you.

Senator ROCKEFELLER. Congresswoman Kelly, I feel slightly demeaned by your statement, and I am sure that Chairman Gramm also feels slightly demeaned, that you would simply throw out to us the number of people in our—I happen not to come from a district, it is called a State. It is called the State of West Virginia. I am quite aware of the figures.

But simply throwing the figures at Senator D'Amato, Senator Gramm, or myself, is not usually the best way. It implies ignorance on our part, assumes ignorance on our part, assumes lack of interest on our part, and is not very persuasive.

Congresswoman Kelly. Senator, I do not mean to demean you in any way. What I am concerned about, is that you understand these are living, breathing human beings who count on you.

Senator GRAMM. Thank you very much, Congresswoman. Let me thank you, Congresswoman Kelly.

Let me thank our panel. I thought it was an excellent panel.

Senator D'Amato, let me recognize you, first.

Senator D'AMATO. Oh, am I first?

Senator GRAMM. Well, of the people who were here, you were here first. You were the first member of the subcommittee to come.

Senator D'AMATO. Mr. Chairman, I thought that you would proceed with the questioning. Yes. Let me thank you, Mr. Chairman.

Mary McCarthy, studies have documented the fear of losing a breast as a leading reason why women do not participate in early breast cancer detection programs. I think you have cited some of those figures. Do you agree that, with breast cancer reconstruction, which is one of the elements that we call for that would not be viewed as cosmetic, it would be provided in the policy?

Do you agree that with that option available that more women would participate in early detection programs and that discovery of cancer at an earlier stage would result in more lives being saved?

Ms. MCCARTHY. I have been surprised as I talk to women that the level of information on breast reconstruction is relatively low. I do believe that, with more information, both the very fact that breast reconstruction is possible and available, that, indeed, it takes much of the fear, one aspect of the fear, of breast cancer from women and makes them less afraid. I am also surprised at how frequently women tell me they are afraid to go in for that mammogram.

Senator D'AMATO. Then I would like to raise that point and say to Ms. Shockney, and I certainly commend you for your leadership in this area, do you not see that as a very positive educational tool? You talked about the role of education. You cannot mandate it, but certainly you would not be opposed to a provision that says that reconstructive surgery is not cosmetic. You would not oppose that, would you?

Ms. SHOCKNEY. No.

Senator D'AMATO. And do you see the holding out of this as a benefit to induce more women to earlier participation and detection? Is that not the kind of thing you will go about promoting in terms of health, and providing for themselves, and alternatives so that they would be less susceptible of hoping that it will go away and more anxious to find out because they know that even if it is detected, there is reconstructive surgery that is possible? Is that not a benefit in this bill?

Ms. SHOCKNEY. We certainly at Johns Hopkins do prove as part of our educational program information for women, including women who do not have breast cancer—or maybe I should say breast cancer yet, since it affects one in eight—what types of reconstructive surgeries are available. I am not completely confident though that it will reduce a woman's fear, because one of her primary fears is that of dying. It is not just having a segment of her breast or all of her breast removed.

Senator D'AMATO. You certainly are not opposed to that provision of the bill though that would call for reconstructive surgery, are you?

Ms. SHOCKNEY. No, I do not have a problem with that.

Senator D'AMATO. Dr. Wilensky, you talk about, and I look at page 3, you say, "The role of the Federal Government in areas that traditionally have been under the domain of the States," that is one of your concerns.

Dr. WILENSKY. Right.

Senator D'AMATO. Right?

Dr. WILENSKY. Yes.

Senator D'AMATO. All right. Now, is it not true that in this particular case the State of New York, or any other State, is precluded as a result of ERISA? In other words, you are saying on one hand, no Federal legislation. You say, "This raises a series of concerns." You know this. "Concerns about the role of the Federal Government in areas that traditionally have been under the domain of States." Right?

Dr. WILENSKY. That is correct.

Senator D'AMATO. That is your concern.

Dr. WILENSKY. Well, that is one of my concerns.

Senator D'AMATO. However, in this particular case, is it not correct that the States are precluded from control because of a Federal preemption? Is that true or not?

Dr. WILENSKY. It is true for only those health plans that are covered by ERISA. As you well know, with managed——

Senator D'AMATO. Is that not what we are talking about?

Dr. WILENSKY. No.

Senator D'AMATO. Well, that is what we are talking about.

Dr. WILENSKY. Your legislation covers all private health care plans, including those that come under ERISA preemption.

Senator D'AMATO. Yes.

Dr. WILENSKY. As you know, States like New York and Maryland, in fact, require coverage for reconstructive surgery whenever there is coverage for removal.

Senator D'AMATO. I am sorry, Doctor, that you were not here before when I testified to that. I mean, I authored this legislation. I drew it.

I did it on a State basis as well as this. We passed it in New York this past year. But 50 percent of the women who are covered by health care plans are not covered as a result of ERISA. Consequently, that is why we have come forward, to cover that 50 percent.

So, given the fact—and I accept your conclusion that you have concerns about the role of the Federal Government in areas that traditionally have been under the domain of the States—would you not concede that in this particular case that we are attempting to address a problem that States cannot address, and that is providing basic protection in this area for those who are self-insured?

Dr. WILENSKY. Mr. D'Amato, the issue of ERISA protection and whether or not the Federal Government ought to make changes as it relates to health care is a very big issue. It is, to my mind, something that, when and if the Congress wishes to take it up, it ought to do so. There have been concerns raised for the last two decades. I do not think it is a good way to take it up on a disease-specific basis.

Senator D'AMATO. Well, Dr. Wilensky, I am just—and it is Dr. Wilensky—referring to your statement on page 3 when you say, this raises a serious concern about the role of the Federal Government in areas traditionally under the domination of States. Would you not concede that, as it relates to those self-insured that fall under ERISA, that the States do not have control?

Dr. WILENSKY. That is true. The other 50 percent are under the State's control. This affects all of them, those who are under the State's control and those who are exempt because of Federal legislation.

Senator D'AMATO. Sure. So we are trying to take care of 50 percent.

Dr. WILENSKY. One hundred percent. You are trying to take care of the 100 percent, 50 percent of whom are already——

Senator D'AMATO. Well, there are 50 percent that the States can take control of, 50 percent in New York's case, and in most States it is about 40 percent, that they cannot.

Dr. WILENSKY. Well, you are taking——

Senator D'AMATO. But I see we are arguing round and round, and I did not mean to engage us in that kind of thing. We do not have nearly enough time, and my other colleagues have been more than patient. I want to thank the Chairman.

But I would like to make an observation. That observation is, Mr. Chairman, that I do not see one element in this bill that impedes education, that makes any requirements, that says that you must stay X number of days or hours, that would interfere with education of patients and patients' rights. Indeed, it sets out standards it says patients will have with their doctors.

Now, if we are going to say that the doctors are not practicing good medicine, then maybe we have to educate them. But to suggest that this bill that holds a very special relationship and protects that relationship between the doctor and patient and says that is sacrosanct, no insurance carrier should be able to interfere with basic medical decisions that have to be left, and should be left, properly, to the doctor and the patient. That is what this bill does. It does not do anything more than that.

It does say that a certain procedure, and if anyone wants to argue to that and suggest that people should not have, and that women in particular, cosmetic surgery, they are going to say that cosmetic surgery is reconstructive, I have never heard of any.

I mean, some people have actually been denied. Mary McCarthy came to me. The reason we put the reconstructive provision in this bill is because she came and related that. Initially when we drafted it we did not have that. She said, I, Senator, was denied reconstructive surgery because they said it was cosmetic. It was shocking. Incredible.

So the fact is that insurance providers were denying people that. I mean, are we going to say that? Or should we not say, wait a minute, that is a basic right that people have.

What about second opinions? Should they not have a right to second opinions? God help any of us if one of our loved ones is diagnosed. I am relatively sure that we would seek our a second opinion. We would find the resources to do that if our policy did not provide. But there are many Americans who do not have those resources.

So when I look at it and analyze it, I see just basic minimums that fair play would call for, particularly when it comes to more than just something of a passing interest, but health of our loved ones. I think it is common sense.

It is too bad that we have to provide legislation, that you would not think that all providers would have this minimum. These are minimums. I do not see anything intrusive in this legislation whatsoever, but rather protective of those rights that I think everyone has a right to expect and, up until recently, I think we rather enjoyed. Nothing says that a person has to stay here a day, 2 days, 3 days, or we would stop outpatient treatment. These are decisions that can and should be made by the patient and the doctor.

I want to thank you, Mr. Chairman, for your not only calling this hearing, but your extending yourself in the manner in which you have.

Senator GRAMM. Thank you, Senator D'Amato.

Senator D'AMATO. I want to thank all our panelists as well.

Senator GRAMM. Thank you.

Senator Bryan.

Senator BRYAN. Thank you very much, Mr. Chairman.

Dr. Wilensky, I would like to follow up on the line of questioning by Senator D'Amato. You have a deep and impressive history and background in public health policy.

From a public policy perspective, what is wrong with saying that essentially the care that is to be provided to a mastectomy patient should be determined by the physician and the patient herself as to both the length of time and what is medically appropriate?

I do not have your background and obviously do not have your depth of understanding. But who else ought to be making that decision as a matter of public policy but the woman and her physician that are most familiar with the circumstances of the individual patient?

Dr. WILENSKY. I think this legislation takes the Federal Government in roles in which it would be better to stay out, as I was trying to share with Mr. D'Amato, the issue as to whether or not States ought to require specific types of mandates is something that States ought to require and be allowed to do for its own citizens.

He is very correct about the ERISA preemption issue. This is a very big issue. In health care, it is something that the Congress threatens or indicates it may take up from time to time, but has not done so. It is an area with respect to that provision that I would regard as being most appropriately left to the States. With regard, of course, to the other two provisions, those are, in fact, mandated coverage.

But, with the issue about having decisions left to the physician, that is appropriate. In fact, as best I can tell, in general, that is the case. That is certainly the case, as best we can tell, by looking at where mastectomies occur in terms of inpatient and outpatient as we look across various types of managed care, HMOs, other types of managed care versus fee-for-service. In terms of the numbers, if anything, managed care appears to be less likely to use outpatient, not more likely.

Senator BRYAN. So your objection is philosophical in terms of the role of the Federal Government.

Dr. WILENSKY. With that particular provision.

Senator BRYAN. One can understand that. And, because my time is limited, I do not want to be rude and abrupt with you, but assuming that the legislation simply applied to those health care providers who were under ERISA beyond the purview of States to provide any, would your objection be the same?

Dr. WILENSKY. It would not be on that particular provision. But I would urge you to make a much broader decision about what you want for ERISA preemption. It is a very big issue. Doing it on a disease-by-disease basis is a very hard way to do it.

Senator BRYAN. Again, from a public policy perspective, is there anything wrong with indicating that a woman should have a right to a second opinion with respect to a disease which is as traumatizing and potentially life threatening, as a matter of public policy?

Dr. WILENSKY. As a matter of public policy, the question is whether or not it should always be paid by insurance. In fact, again, at least to my anecdotal inquiries, is that, particularly in places where they are responsible for further care, like in managed care, they tend not only to cover them, but usually to require them.

But the question is, yes, I think women should have them. Whether or not we ought to require that all insurance pays for this is, again, something I do not believe is the prerogative or responsibility for the Federal Government.

Senator BRYAN. And your view on the reconstructive surgery?

Dr. WILENSKY. Well, I have actually more knowledge in this area. I happen to be the spouse of a plastic surgeon who engages in reconstruction for cancer surgery. I believe that it is an important way to try to help women through the trauma.

I do not believe that it is going to fundamentally change some of the statistics, because of my information about what has been going on in Medicare where we have abysmally low rates of mammography, although there is coverage, and it is primarily in traditional fee-for-service.

Again, the question is not whether or not it ought to be there, it is whether or not it ought to be a required element of any insurance policy that is offered.

Senator BRYAN. But you would concede that there are women who are denied the right to second opinion, and you would concede, would you not, that there are many women——

Dr. WILENSKY. Denied the right, no. The question of whether or not there is any insurance coverage and how many that do not pay for them that pay for the first inquiry, is a different matter.

I do not know how many HMOs, or other managed care, do or do not cover second opinion. My understanding is, it is common practice. In fact, in many plans it is required in the plan.

The question is not a question of denying the right, the question is requiring that insurance must pay for it, pay for it fully, pay for it on whatever grounds other inquiries to physicians are made. That is a very different issue.

Senator BRYAN. Ms. Shockney, if I might ask you a question. Johns Hopkins enjoys, and deservedly so, a reputation as one of the outstanding medical centers in the world. At the turn of the century you paved the way for the framework for modern medical education, the Flexner report, that I know the Chairman is very much familiar with.

So I was a little surprised, if I understood you correctly, to be arguing against a part of this bill on the basis that, if I understood you correctly, that if we had provisions that required individuals to be permitted to stay in a hospital setting based upon the advice of her physician, that somehow that would discourage health care professionals from improving patient care. My son is a cardiologist. I happen to think that most health care providers in America try to do the very best that they can for their patients.

I must say that I was somewhat shocked. It struck me as being an indictment of the medical care profession. I do not know whether I understood you correctly, but I cannot conceive of the logic that this legislation would somehow discourage medical care providers from providing improved care as new techniques, knowledge, or information becomes available. So let me give you an opportunity to respond to that.

Ms. SHOCKNEY. Certainly. If a patient has the option to stay in the hospital several days versus going home the same day as surgery or the day after, for a woman who is having a mastectomy without reconstruction, there is a higher need for patient education and a higher need for more innovative practice for surgical management and anesthesia management, the shorter the length of time that the woman is hospitalized.

If the patient says, I would really like to stay in the hospital until my drains are out, she is probably not going to get educated about her drains, she is probably not going to get the degree of information about her disease and treatment plan because she already has made a decision herself, without having good knowledge yet, that that may not be what is best for her.

I am telling you, I have seen across this country a wide variation, and I have heard it from almost everyone today, of someone will tell some horror story related to care. That tells me that we are not addressing the issue which is, what are we going to do to define best practice, what are we going to do to determine what is the best care, having the patient stay in for an undefined period of time that may not be in her best interests medically.

Senator BRYAN. I think you would agree that it would be difficult, if not impossible, for us to describe and define legislatively best care. The language that Senator D'Amato and the sponsors have provided seem to me to be a reasonable standard, if I can get you to respond to that, and it simply says, to paraphrase, that the patient stays in, provided for for a period of time, as determined by the attending physician, in consultation with the patient, as is medically appropriate.

Now, again, I am not a health care professional or a public policy individual. Who else ought to be making that determination? It seems to me it ought not to be the green eye-shade fellow in the back room there with the HMO. The patient and the physician will know the individual circumstances, and I suspect that they differ from woman to woman.

I would imagine that there are various degrees of surgery that are required, so what may be inappropriate length of stay for one would be highly appropriate for the other. Again, help us, if you do not like this language, and I want to give you an opportunity to respond, what language would you suggest be placed instead?

Ms. SHOCKNEY. I strongly believe that the decision does need to be made by the physician and the patient, and preferably have that be jointly done. However, if we are not insuring for women, and Mrs. Kelly commented about it, and I felt the need even to write it down, "that this bill will safeguard quality of care." No, it will not. It will not safeguard quality of care, it will promote the status quo. We will continue to hear wide variances across the country as to the treatment experience that a woman had having had her surgery done.

Senator BRYAN. Thank you very much.

Thank you, Mr. Chairman, for convening these hearings.

Senator GRAMM. Thank you.

Let me go ahead and ask a couple of questions now and then make a few remarks, and then I will recognize Senator Rockefeller. We are going to have a vote here right after 4:00, so I think we that way can complete our hearing.

First of all, I was looking at some data, and I think Bismarck once said, "Never does a politician stand on firmer ground than when he argues for the best principles of health." Clearly, the high political ground on any of these debates is to be for the maximum amount of health care under any circumstance.

Unfortunately, the logical decision has to always be made in terms of the alternatives that are available and it is a very difficult issue to debate. We received some instruction from Congresswoman Kelly about the number of people who were affected in our States. I think we are each aware of that.

I think each of us in our own family have, in all probability, been affected by this problem. Rather than getting into it as if it needs to happen to you for you to be able to understand it, I do not want to burden the committee with that.

Basically, what we have to do on this committee is determine what the facts are. I noticed, for example, in looking at the data on New York State—and New York State has excellent data and I think their State should be proud of it—in 1995 there were 7,016 mastectomies performed in the State of New York. Only two of those were outpatient mastectomies that were performed in HMOs. Two out of 7,016. Now, you might say, well, that is two too many. What we are going to do is try to find those two people and ask them.

Gail mentioned that 74 were performed under Medicare. So I think, first of all, we have got to find out, is this a real problem? Now, you have got two people in the State of New York in 1995, apparently our last data point, who are in HMOs. Apparently this is the problem area that is being addressed by this bill. They are in HMOs and they had outpatient mastectomy.

We want to try to find those two people and find out how it happened, what their experience was. We want to try to look at the national data to see if this is, in fact, a real problem or one that we feel for and we would like to deal with, but that, in fact, is not a problem that actually exists anywhere.

I would like to ask each of you a question.

Senator D'AMATO. Mr. Chairman, if I might. I say this with all due regard to the fact that a member, during his or her period of time, can raise any question or make any statement. But I think it is really a mischaracterization, if it is your intent—and I hope it is not—to suggest that this legislation is aimed at dealing with outpatient mastectomies, because no where do we speak to that. Rather, we talk about medical treatment and procedure and, as it relates to length of stay, that it should not be.

We did not say that there are outpatient mastectomies that are taking place, et cetera, or lead one to believe that. What we said was, the procedure of treatment and the length of stay should be determined by the doctor and the patient.

Now, no one suggested, and I certainly did not, I did not hear any of my colleagues suggest, that outpatient mastectomies are taking place, that they are rampant, et cetera. So I would suggest that is almost a red herring and it is not fair.

Senator GRAMM. Senator, now wait a minute. I have listened to all this testimony. I am simply making a point about people who had mastectomies and went home the same day.

Senator D'AMATO. Yes. But no one is——

Senator GRAMM. The point I am making is, and I am on my time, and I am Chairman of this subcommittee.

Senator D'AMATO. Fine.

Senator GRAMM. All right. Now, the point I am making is——

Senator D'AMATO. That generally happens when a question is raised or proposed and we have difficulty in responding, then we can go back to those technicalities.

Senator GRAMM. Well, Senator, I am in the process of asking questions to the witnesses. I am going to have to insist that I be able to do that in my own subcommittee.

Senator D'AMATO. Certainly. Oh, certainly.

Senator GRAMM. Now, the point that I was making is, is part of what we have got to do is to try to determine what the facts are. One of the things I do not know, is we have heard talk about second opinions. I would like to ask each of you this question. Do you have any data on the number of HMOs that do not allow second opinions?

Dr. WILENSKY. I do not. I think it is very small, if it existed. I could find that data. I do not have it in my head. When I have asked, as a result of the legislation, I made just some inquiries, and the response was usually, not only do we cover it, we usually insist on it, because they also want to make sure this is appropriate surgery. But I do not know, empirically, what percentage cover the second opinion.

Senator GRAMM. Ms. McCarthy, in New York, in your work, do you perceive that it is common that HMOs do not provide for second opinions or ban it in terms of their coverage?

Mc. McCarthy. I think an important distinction as it relates to this bill is the ability to go outside the HMO for your second opinion because when you have a disease with the magnitude of cancer, while the other oncologist in your group or the oncology group across town may be a good group, you want the perspective and the expertise of going to a major cancer center.

It is the fact that so often a second opinion for a cancer diagnosis and treatment means going outside the HMO. That makes it a particular issue and concern and the reason why legislation, in this case, is appropriate because the HMOs, as you know, are often very reluctant to authorize those out-of-plan referrals.

Senator GRAMM. Ms. Shockney, do you know any data on second opinions?

Ms. SHOCKNEY. I do not. However, specifically for Johns Hopkins, I am not aware of any problems that our patients have experienced in seeking a second opinion.

I would like to add to that that for facilities that are comprehensive cancer centers that have been given that designation by the Commission on Cancer, as part of the standards built into being able to be called that special title, if a patient is diagnosed with any type of cancer, no matter whether it be breast or some other type, they automatically get a second opinion there at that comprehensive cancer center without any cost incurred to them or to their insurance company, because the standard requires that a multi-disciplinary team review each and every case and do a case conference to determine what will be the best care for that particular cancer patient.

Senator GRAMM. Ms. Visco?

Ms. VISCO. Well, there are, I believe, data to show that it is not medically appropriate to get your second opinion in the same institution; you are just hearing the same thing twice. But I am not aware of data, I am aware of many anecdotes. But I am sure the data are available.

Senator GRAMM. Well, one of the things that I hope we can do between now and the first of the year is really determine, number one, what is the standard procedure in terms of mastectomy, how many we have on an outpatient basis, are those chosen by the people who choose that type of service, what is their experience; to what degree is the absence of a second opinion a problem.

The final couple of points I would like to make, and over and over we have asked about people's right to make a choice. There is only one medical practice in America that is forbidden. What we are being asked about choice here is that someone has entered into a contract with an insurance company, and what is being called a lack of choice is that that contract does not pay for a service that they feel they should have.

The only outright prohibition in the country is the prohibition, under Medicare, that precludes an individual citizen from contracting with a health care provider directly. That is forbidden. But none of these other things are forbidden.

The question, really, for us boils down to this, it seems to me. In many States around the country we have had States get into the business of legislating, what is a good health insurance policy.

The problem with that, is that almost any benefit benefits someone, and they are often crucially important, mental health benefits, for example, drug rehabilitation. Anyone who has ever had any experience with children who are on drugs, or adults who are in alcoholism. These are benefits that, if you need them, are sent directly from heaven.

But the experience of the States has been that, in trying to create this perfect insurance policy, they end up with costs that often rise substantially. Then you end up with people who have moderate incomes who end up not being insured because they have got to carry drug rehabilitation and alcohol rehabilitation in order to buy a policy.

I think what we want to try to determine—and I want to urge anyone that is here who has data, it would be helpful to us if they could provide it to the committee, and I know we have many people here who are experts in this area—any data on the general practice of limiting access to the hospital on mastectomy, any practice of limiting second opinions.

I think those are things that we would very much like to know more about and have more data on as we move forward to considering this bill. I think we all want to help Americans have the best insurance that we can see them have.

The question we always face, however, is that, in trying to improve the individual policy, we have to be sensitive that we do not price some people out of the market. That is the constant problem that you always face.

It is like mandating that houses be constructed in a certain way. I mean, who is against the finest quality house? But the problem is, tens of millions of Americans cannot afford that house.

If we have got to build a house that we think would be of the standard that we would all want, the bottom line is, many of the people who do not have that standard would not have the house.

That is the hard decision we have to make on a very, very tough issue, and one that obviously, when people face it in their personal lives, is really a life-altering kind of experience. I think each of us is very sensitive to that fact and understands it. I think, to the best of our ability, we are going to try to look at this and try to find, what is the right thing to do?

The obvious trade-off is between the rights of an individual to enter into a contract and picking and choosing as to what services they think they need versus services we may conclude they need, or medical practice as it evolves, as you have said, Ms. Shockney, as compared to how we think it should evolve. I think those are all the difficult questions that go with a policy which is very difficult to object to in terms of its objective.

Senator Rockefeller?

Senator ROCKEFELLER. Thank you, Mr. Chairman.

This is, in fact, I think, an incredibly, not only important, but very interesting dilemma that policy makers face. On the one hand, we have the drive-by delivery bill, which the Congress passed. Now we have this. From a philosophical point of view, I am torn from two directions.

Number one, I do not think that it is necessarily the wisest course for health care public policy to be determined by men and women, at least in this body, only one of whom is a physician.

On the other hand, if people are getting treatment which is inadequate, from either their point of view, or perchance should it be persuasive to us, then the question is, who is going to respond to that?

The ERISA matter is very large, as Gail Wilensky knows. I mean, less than half of all Americans are regulated in terms of health care by States. Whether or not we deal with ERISA, we have to deal with the fact that less than half of Americans have protection from States. States are not precluded, but they are not required, Senator D'Amato, to include mastectomies.

Then PPRC says, as some of you have indicated, there is very little evidence that outpatient mastectomies are common. AAHP says only about 8 percent of all mastectomies were done on an outpatient basis. Another study found that patients were no more likely to receive an outpatient mastectomy in a managed care plan than under fee-for-service.

Now, I go from that kind of array of inconclusive results to what often I have to make decisions based upon, and that is partly my head and partly my gut. In terms of my gut, or my soul, I have got to deal with people that I know. I can think of a few people that I know who have been through this process. Ms. Shockney, this is one where I would be interested in your view.

One person I am thinking of, a woman in her 30's, she, as so often happens, I think, when we are hit with a traumatic disease of some sort, I would think in some ways this might be typical, but I do not know, went through a long period of denial that she had breast cancer, or that there was anything that was really threatening about this.

You could not make a really clear explanation of why she was denying something when it was right there on the X-ray and she knew and she had agreed to go into the hospital to have her breast removed.

But, nevertheless, the denial mentality stayed in a very, very rational, down-to-earth, grass-roots person. It did not leave her until she came out of anesthesia, at which point she took a tremendous downward plunge psychologically.

It was not that she was not doing fairly well physically and that she might, at Johns Hopkins or some other place, have been discharged in 6 hours or 6 days, it was the fact that, mentally, she really was not—at one point, or several points in fact, she asked us to leave, those of us who were visiting her, because she just could not cope.

That is a part of procedures, just the human reaction to, finally it hits you, it really has happened, I really have lost my breast, and oh, my God, I did not think it was going to be like this. Yes, it hurts a lot, but all of a sudden, all of the worries about the future.

So if Johns Hopkins can do this in a 6- to 8-hour period, if the operation takes 45 minutes, et cetera, still, there are these other factors to consider. I cannot approach them, other than on an anecdotal basis, except by looking at these statistics which do not push me.

Philosophically, I do not think that, again, a Congress ought to be saying that there ought to be 48 hours required, because I am not sure that 48 hours is it. On the other hand, if Senator D'Amato's bill goes to the floor this afternoon, I will vote for it because I do not want to take a chance, as a public policy person, that my own lack of understanding, anecdotal or learned, deprives somebody of care that they might need.

I know that, in the case of this individual, that she needed to be in a hospital for several days. Physically, I cannot talk about whether that was required, but emotionally, I guarantee you that she had to be there.

So my question to you is, and I guess I will just make this my only question of you because of time, is how does Johns Hopkins handle the denial syndrome and the post-operative emotional traumatic effect of that being reversed, and still manage to maintain the policy that you do?

Ms. SHOCKNEY. Denial is a very normal process for any patient to go through who is confronted in a life-threatening situation, whether it be cancer, a heart attack, or some other illness, multiple sclerosis, for example.

One of the most important things that needs to be done and that we do for our patients at Hopkins is to do a psychological assessment of the patient and her care partner. Her care partner might be her spouse, it could be her mother, could be her sister. That is done at the time that the patient is initially seen and diagnosed.

She is then partnered up that day on the day that she gets her news with a Johns Hopkins breast cancer survivor volunteer, and I am responsible for that survivor volunteer program.

I match the patient who has been newly diagnosed with a woman who has been diagnosed and treated at Hopkins and is doing well. So if we have a woman between 35 and 40 newly diagnosed, Stage II disease, is going to have a mastectomy, I will match her up with someone who is also that same age, same disease stage, and also having the same treatment, so that she has a psychological partner to help carry her through.

Now, we also have a cancer counseling center specifically for providing psychological support, and the surgery is not going to happen until we have done a good job of preparing that patient psychologically. I feel very bad for your friend, just in hearing you describe that.

I am not confident, though, that she got her psychological needs met by being in the hospital, being taken care of by people that did not know her until she was hospitalized. I would like to think that that is better done, and it was certainly in my own case, having had three breast cancer surgeries, was better done by my family and my friends in my home.

Senator ROCKEFELLER. And by the partner.

Ms. SHOCKNEY. Yes.

Senator ROCKEFELLER. I mean, I like to think that we all did the best we could. But it sounds to me like you have introduced something very important, and that is the partner.

Ms. SHOCKNEY. We call it the care partner.

Senator ROCKEFELLER. A care partner with a successful experience so that they do not allow denial to last very long because they are going to see their——

Ms. SHOCKNEY. We try our best. I think that it is one of the most important things that we need to help women to overcome the denial, is to see that you can survive this disease.

So when you have got standing in front of you someone that says, I have been where you are right now exactly where you are, and I am alive today, and I will get you through as best I can, to psychologically leap over these hurdles that you are about to cross. She will be able to tell her candidly when a hurdle is coming, which a medical physician is not able to do because he has not, unless he himself has had breast cancer, which does not happen too often, would be able to provide that type of candid support.

Senator ROCKEFELLER. A final point. Excuse me, Mr. Chairman.

Ms. Visco, what Ms. Shockney is describing, is that fairly common, or is this kind of care partner fairly unusual?

Ms. VISCO. It is a very unusual situation. If the Johns Hopkins model worked for every woman and were implemented everywhere across this country, we would not be here. But that is not reality.

Ms. SHOCKNEY. I do not know why we cannot make it reality.

Ms. VISCO. But while we are working to make it reality and hoping that it does work for every woman, we need to have these safeguards in place because it is going to take a long time to get there.

Senator ROCKEFELLER. Thank you very much.

Senator GRAMM. We have a few more minutes before we are going to have our vote. Senator D'Amato, if you wanted to make some additional points or ask some questions, we would be glad.

Senator D'AMATO. Well, thank you, Mr. Chairman. I would just like to make this one point, and I appreciate the time constraints.

When we look at this legislation, let me give you a little history. When we first drew it, because it was in response to, I think, the anecdotal stories about people who were not given sufficient time, and the drive-by mastectomies, you began to read and hear about them anecdotally.

We had a time. We said, you have at least 24 hours or 48 hours. I think the initial bill said 48 hours. We circulated this throughout the medical community, throughout the patient advocacy groups, as Ms. Shockney pointed out, and spoke to patients themselves, the survivors.

They came back very clearly, and as a matter of fact, Senator Feinstein said, I can support this, but I am not sanguine and happy with putting a minimum in, or at least 48 hours that a person would be guaranteed. We found a great consensus in the medical community throughout that we should not time line it.

That goes to the point that Senator Bryan made. In this legislation we are very careful to say, and I will just repeat this, that health insurance coverage, in connection with a group health plan that provides medical and surgical benefits, that shall ensure patient coverage with respect to treatment of breast cancer, is provided for a period of time, as determined by the attending physician in consultation with the patient, to be medically appropriate.

Patient and physician, to be medically appropriate. We should not be trying to determine. If new standards, procedures, and methodologies are achieved, well, obviously the doctor and the patient will determine.

So nowhere did we attempt to suggest that there was this problem with people being pushed out within 24 hours, et cetera, but there were anecdotal and other problems related, and even the fear that the person might not be able to stay an appropriate period of time. I, in no way, see this as an intrusion, but rather setting a marker of a minimum standard.

Indeed, it goes on. If you read the other section, we say that with respect to this that, "Nothing shall be construed as requiring the provisions of inpatient coverage if the attending physician and patient determine that a shorter period of time."

We specifically want people to know, if they want to go out within two hours, four hours, six hours, and it may be very appropriate, fine. That is a determination that should not be made by the Congress, or particularly a bean counter who is going to try to save money.

How could we logically believe that someone can say, this is the period of time we will cover. It may be that the average length of stay is 3.6 days, and I think that is what it is in New York, about 3.6 days, from the last testimony we had from one of the great teaching facilities, the Sloane-Kettering people made a study.

Indeed, it may be 3.6, but some may be able to be discharged within 24 hours or 36 hours, and others a longer period of time. But, again, I think this is minimum legislation. I do not see it as intrusive. If we did not have the problem with ERISA and, indeed, the Senator may look at just covering the ERISA area, we could amend it to do that so that States can, if they want, prescribe more or less with those who are not preempted by ERISA.

But right now we are preempted by ERISA in terms of, and that is between 40 to 50 percent of our people, are precluded from these basic protections. Those carriers or HMOs that this does not present a problem to because they are already doing these things, then fine, they should not stand an objection. To those who are not, we say that I think we have a right to set a minimum standard.

I appreciate the consideration of the committee and the time of the Chairman. I look forward to working together in a manner which will ensure these basic minimum standards.

I want to thank the witnesses, all of them, for giving of their time and sharing with us their expertise and their insights.

Senator GRAMM. Let me ask, does anyone else on the committee have any question or comment they would like to make?

Senator BRYAN. Mr. Chairman, could I ask just one question?

Senator GRAMM. Sure.

Senator BRYAN. I think, as you were reflecting upon the experience at the State level, much of what you said resonates with me. I have had some experience at that level, as you know. You do raise the question of the States in trying to provide more comprehensive medical care plans, and have done the very thing that you have suggested to require the inclusion of drug and alcohol rehabilitation.

Everyone in this room fully understands that it is a national problem, some would say a crisis, so we have added that, and mental health care. As a result, those plans have become extremely costly. I think that is one end of the public policy spectrum.

On the other hand, I would suggest that the focus is to the number of outpatient mastectomies that have been performed does an injustice to what I think the Senator is trying to do here.

I mean, I think the focus is really, are women who experience this traumatizing medical diagnoses and operation, are they getting the kind of quality medical care they deserve? I think all of us want that to occur. I believe that there is a sufficient amount of evidence to indicate that many are not, because of some of the public policy imperatives that are the very nature of the HMOs themselves. I think you, Mr. Chairman, make a point that we need to have a data base. I think that is a realistic and honest assessment.

My one question, if I may, since we have the benefit of Ms. Shockney, what is the average length of time that a woman who undergoes a mastectomy stays in the hospital as an inpatient at Johns Hopkins, and how does that correspond with the experiences in other medical institutions, if you happen to know?

If I could just add one gratuitous observation, it is my sense that as a result of the public policy decision that this Congress has made for more than a decade now trying to reduce, in general, the length of inpatient hospitalization across the whole spectrum of medical services, that probably we have the world's shortest length of stay in hospital for procedures compared with other advanced and sophisticated countries that provide medical technology. Would you happen to have the answer to either of those two questions?

Ms. SHOCKNEY. I can give you some information on each of those questions.

Senator BRYAN. And I thank you, Mr. Chairman, for allowing me.

Ms. SHOCKNEY. I was curious when you mentioned about the length of stay being, I think you said, 3.4. One of the problems that we have with DRGs, specifically with mastectomy, is that it does not factor in whether or not the patient simultaneously has had reconstruction. So, you need to separate out those that were mastectomy alone from those that were mastectomy and simultaneous reconstruction.

Eighty-one percent of our patients who have mastectomy alone without simultaneous reconstruction go home the same day, and it is the patient's choice. Eighty-one percent. Last year, it was between 65 and 70 percent. Our patient satisfaction scores continue to go up, reaffirming for us that we believe we are providing good care for these patients.

Senator BRYAN. You also have an outpatient program with that as well, do you not? I do not mean to interrupt your answer, but, I mean, I thought I gathered from your testimony that Johns Hopkins has a very comprehensive program for outpatient follow-on.

Ms. SHOCKNEY. Right, to ensure continuity of care. The way in which we are surgically performing the procedure, as well as the type of anesthesia management that is done, is different than is happening in other places.

It was initiated because a patient said, if I just could have gotten rid of that nausea and vomiting I would have felt so much better that first night. So we worked hard to figure out, how can we eliminate nausea and vomiting, and took our rate of nausea and vomiting from 87 percent down to 3 percent. It is good to wake up and not feel like you need to have your head in a bucket, for heaven's sakes.

Senator BRYAN. I guess, to play the devil's advocate for a moment, with that extraordinary statistic that you just shared with us, one might say that the language that Senator D'Amato and his colleagues have incorporated into the legislation really would not change the circumstances at Johns Hopkins because these are decisions that you have indicated are made by the patient and the physician.

I do not think any of us in the room would disagree with that. If that kind of care is provided, that is a great tribute to the medical service that you are providing at Johns Hopkins.

Ms. SHOCKNEY. That is very true. This bill would not affect the care that breast cancer patients receive at Hopkins. However, I am concerned, as I mentioned, that it may impact improvements of care in other facilities because there is not going to be this strong incentive to eliminate nausea and vomiting and have the patient go home sooner when she could feel better.

Now, back to your original question. For women who have mastectomy with an implant, tissue expander is one form of reconstruction, they are the majority of the time overnight patients.

Women who have mastectomy with what is called a tram flap, what I call the industrial-strength reconstruction, where the abdominal tissue is tunneled and implanted up on the chest to build a breast mound, their average length of stay at Hopkins is 4 days.

We have an international office at Johns Hopkins and we do see a lot of breast cancer patients from foreign countries. We also are visited by physicians from foreign countries. We have had two countries there, in October, as a matter of fact. You are right, the length of stay is longer.

In one particular country, their length of stay is the way in which we did it here in the United States 50 years ago. So, they are always surprised when they come over here and see how very different things are, but they are excited about it and want to implement it, which I commend them for wanting to do.

Senator **Gramm**. Let me just say that, in terms of trying to determine what the facts are, I am sure all our colleagues will remember when we had this long debate over the so-called "gag rule."

Well, as turned out, when we went out and tried to gather data, and certainly I always stand subject to being corrected, but I do not think we found a single HMO in America that had a gag rule. But we had extensive debate about it. So I think obviously part of what we want to do, if the subcommittee has any relevance at all, is to try to gather facts and make a rational decision.

I want to thank each of you for coming. I especially want to thank you, Ms. Shockney. Johns Hopkins is a great university, has a great medical center. If I could buy a policy that guaranteed the right of my wife to stay in the hospital longer or buy a policy that guaranteed her right to be treated by you and your program, I would choose being treated by you and your program.

Really, part of what we are deciding is preserving that freedom, about what it is that is important to each of us. These are the things, obviously, that we have to iron out in a very, very tough issue area. I want to thank each of you for coming. I thought the panel was excellent. Thank you all very much. Thank you.

[Whereupon, at 4:04 p.m., the hearing was concluded.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

PREPARED STATEMENT OF HON. RICHARD H. BRYAN

Breast cancer is the leading cause of death for American women between the ages of 40 and 55 years. There is a new breast cancer case diagnosed every 3 minutes, and a woman dies from breast cancer every 12 minutes.

This year more than 180,000 new cases of invasive breast cancer will be diagnosed. The unfortunate result is that approximately 44,000 women will die from this disease.

For any woman learning that she has breast cancer is one of life's most frightening experiences. For those learning that a mastectomy, a surgical procedure that will change their bodies and their lives, is the appropriate medical treatment can be devastating.

For those women diagnosed with breast cancer, we need to ensure they receive the best treatment and coverage available, and that crucial health care decisions are left in the hands of doctors, not accountants. many managed care/HMOs send women home within a few hours after breast cancer surgery. Sometimes the patient is still groggy from anesthesia, in pain, and with drainage tubes still in place when they are sent home.

Other women have been denied hospitalization on the day of their surgery, forcing doctors to choose between giving patients the quality care they need or being penalized by the HMO for not following discharge guidelines.

This is why I cosponsored "The Breast Cancer Patient Protection Act" which requires a minimum hospital stay of 48 hours for mastectomies, and 24 hours for lymph node removals.

Women who are already in a vulnerable health situation should not have to face fighting with their insurer over whether or not they can stay in the hospital longer than the day of the mastectomy surgery.

This bill does, however, include an important provision to allow a woman and her physician to make a medical decision together that she can go home earlier, and to thereby waive the minimum stay requirement.

Today's hearing will focus, in part, on whether Congress should proscribe minimum hospital time limits in legislation. I realize this is a controversial issue, but I implore my colleagues to remember who it is we are trying to protect with those minimum time limits—it could be any of our wives, daughters, sisters or friends.

Statement of US Senator Alfonse M. D'Amato
Senate Finance Subcommittee on Healthcare Hearing
Women's Health and Cancer Rights Act of 1997

WASHINGTON -- The following is the prepared opening statement of U.S. Senator Alfonse M. D'Amato (R-NY), at a November 5th Senate Finance Subcommittee hearing on his legislation, the Women's Health and Cancer Rights Act of 1997:

"There is an epidemic in America today. It touches the lives of every woman, every family and every community in our country. The epidemic is breast cancer and it is among the leading killers of women in America. We must put an end to this horrific disease.

"Today, there are 2.6 million women living with breast cancer. In 1997 alone, more than 184,000 women will be diagnosed with breast cancer and, tragically, 44,000 women will die of this dreaded disease. Breast cancer is still the most common form of cancer in women; every three minutes another woman is diagnosed and every 11 minutes another woman dies of breast cancer. The D'Amato-Feinstein-Snowe legislation makes critically important changes in how breast cancer patients receive medical care.

"Mr. Chairman, I come before this Committee today to speak in favor of "The Women's Health and Cancer Rights Act of 1997". This important reform legislation will significantly change the way insurance companies provide coverage for women diagnosed with breast cancer. The problem of the so-called "drive through" mastectomies must be eliminated from our society and Physicians must not be forced to have their best medical judgment questioned by insurance companies who put their bottom line before a woman's health. The women of New York and America deserve better.

"Mr. Chairman, I am very proud to tell you that this bill was recently passed in New York State. While that is great news for the women of New York, I am very concerned that the rest of the women of America are not being given these basic rights. Furthermore, not all New Yorkers are protected either. Because of the division of federal and state responsibilities for the regulation of health care benefits under ERISA, there is a void created in New York which can only be filled by passage of this bill on the federal level.

"As you know, Mr. Chairman, the regulation of health plans has been divided between the federal government and the states. Under the Employee Retirement Income Security Act (ERISA), the federal government regulates self-insured private employer health plans, and prohibits states from regulating such plans. The law allows states to regulate insurance plans offered by insurance carriers, such as Blue Cross/Blue Shield, Oxford and others. Thus, state laws apply only to insurance sold by insurance carriers, and not to the self-insured employer plans used by larger employers. These plans cover as much as 40% of the privately insured population.

"This prohibition on the regulation of self-insured plans has created a two-tiered system in our states. The Women's Health and Cancer Rights Act needs to be passed on the federal level so all enrollees in the various plans throughout the country will be covered by these basic protections.

"Mr. Chairman, this bill is a basic, common sense approach to health care. Specifically, the bill requires health insurance companies to cover an amount of time that is appropriate for hospital stays following mastectomies, lumpectomies and lymph node dissection for the treatment of breast cancer. Our bill makes it clear that the physician determines the length of stay when a woman undergoes a mastectomy. This critical legislation gives every physician the freedom to prescribe longer stays when necessary, and the confidence that insurers will not punish them for practicing sound medical treatment. Our bill would make it illegal to penalize a doctor for following good medical judgement. The time for a hospital stay will no longer be an arbitrary determination made on the basis of saving money.

"Another important provision of the D'Amato-Feinstein-Snowe bill ensures that mastectomy patients will have access to reconstructive surgery. Scores of women have been denied reconstructive surgery following mastectomies because insurers have deemed the procedure cosmetic and not medically necessary. It is absolutely unacceptable and wrong that many insurers have decided that this essential surgery is "cosmetic".

"Very shortly, this Committee will hear from a woman who was denied reconstructive surgery following a mastectomy. Imagine the shock and horror of being told by your HMO that surgery following the removal of your breast is cosmetic. That is outrageous.

"The "Women's Health and Cancer Rights Act" also includes a unique provision for coverage of second opinions by specialists. The bill would require health care providers to pay for secondary consultations when cancer tests come back either negative or positive. This important provision will help identify false negatives as well as false positives. Additionally, if the attending physician recommends consultation by a specialist not covered by the health plan, the bill would allow the doctor to make such a referral at no additional cost to the patient.

"I know that there are going to be those who say let the marketplace work, let free competition work. Well, that is simply naive. To say that by insisting on a minimum standard, insisting on basic common sense minimums we are interfering with the free market system is preposterous. For the government to not live up to its most basic duty of protecting its citizenry, that is what is wrong.

"Mr. Chairman, there exists a very basic relationship between a doctor and a patient that no member of Congress and no insurance bean counter can ever understand. That bond is so basic and so sacred that it is only the physician who is treating their patient that can truly understand it. It is only that physician that can truly determine the best course of action for their patient and knows how to save their life. Congress has a duty to protect that bond and ensure that the physician is able to practice medicine.

"This legislation is crucial not only for the women of New York, where breast cancer ranks among the top in the nation, but for the entire country as well. Our families have been ravaged by this horrible disease. Our grandmothers, mothers and daughters, sisters and wives, children and friends have been afflicted at rates that are unexplained and far too high.

"We must continue to work together, on a bipartisan basis, to find a cure for breast cancer. But until a cure is found, we must ensure that women receive the treatment they deserve. This legislation protects women and anyone ever diagnosed with cancer. It is the most comprehensive bill introduced in the Senate and I am proud to offer it today."

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PREPARED STATEMENT OF HON. DIANNE FEINSTEIN

I appreciate the opportunity to testify today and thank the chairman for scheduling this important hearing.

S. 249, the Women's Health and Cancer Rights Act of 1997, which I introduced on January 30 with Senator D'Amato and others, has four important provisions:

For treatment of breast cancer:

1. It requires insurance plans to cover the hospital length of stay determined by the physician to be medically necessary. Importantly, our bill does not prescribe a fixed number of days or set a minimum. It leaves the length of hospital stay up to the treating physician.
2. It requires health insurance plans to cover breast reconstruction following a mastectomy.

For treatment of all cancers:

3. It requires health insurance plans to cover second opinions by specialists whether the initial diagnosis is positive or negative.
4. It prohibits insurance plans from financially penalizing or rewarding a physician for providing medically necessary care or for referring a patient for a second opinion

TWO CALIFORNIA CASES

Let me share with you two horror stories of California women describing their treatment by insurance companies after having a mastectomy:

- Nancy Couchot, age 60, of Newark, California, wrote me that she had a modified radical mastectomy on November 4, 1996, at 11:30 a.m. and was released by 4:30 p.m. She could not walk and the hospital staff did not help her "even walk to the bathroom." She says, "Any woman, under these circumstances, should be able to opt for an overnight stay to receive professional help and strong pain relief."
- Victoria Berck, of Los Angeles, wrote that she had a mastectomy and lymph node removal at 7:30 a.m. on November 13, 1996, and was released from the hospital 7 hours later, at 2:30 p.m. Ms. Berck was given instructions on how to empty two drains attached to her body and sent home. She concludes, "No civilized country in the world has mastectomy as an outpatient procedure."

These are but two examples of what, unfortunately, is symptomatic of a growing trend—insurance plans interfering with professional medical judgment and arbitrarily reducing care without a medical basis.

Premature discharges for mastectomy are one glaring example of patients and physicians who have to "do battle" with their HMOs to get coverage of the care that physicians prescribe.

NEED FOR THE BILL

Increasingly, insurance companies are dropping and reducing inpatient hospital stays for mastectomies. This is beyond the pale. It is unconscionable.

The Wall Street Journal on November 6. 1996, reported that "some health maintenance organizations are creating an uproar by ordering that mastectomies be performed on an outpatient basis. At a growing number of HMOs, surgeons must document 'medical necessity' to justify even a one-night hospital admission."

A July 7, 1997 study by the Connecticut Office of Health Care Access found the average hospital length of stay for breast cancer patients undergoing mastectomies decreased from three days in 1991 and 1993 to two days in 1994 and 1995. This study said, "The percentage of mastectomy patients discharged after one-day stays grew about 700 percent from 1991 to 1996."

In the last ten years, the length of overnight hospital stays for mastectomies has declined from 4 to 6 days to 2 to 3 days to, in some cases, "no days." With the average cost of one day in the hospital at $930.00, if insurance plans refuse to cover a hospital stay, patients are forced to go home.

In 1997, over 184,000 women (or one in every 8 American women) will be diagnosed with invasive breast cancer and 44,300 women will die from breast cancer. 2.6 million American women are living with breast cancer today. In my state, 20,000 women will be diagnosed with breast cancer and 5,000 will die or one every 27 minutes. San Francisco has some of the highest rates of breast cancer in the world.

After a mastectomy, patients must cope with pain from the surgery, with psychological loss—the trauma of an amputation—and with drainage tubes. These patients need medical care from trained professionals, medical care that they cannot provide themselves at home.

A woman fighting for her life and her dignity should not also be saddled with a fight with her health insurance plan.

BREAST RECONSTRUCTION

, Insurance plans also refuse to cover breast reconstruction. Our bill requires coverage.

Joseph Aita, Executive Vice President and Medical Director of LifeGuard, was quoted in the San Jose, CA, Mercury News, as saying "Looking normal is not medically necessary."

Let me contradict Mr. Aita. Looking normal is medically necessary. Breast reconstruction is important to recovery. According to Dr. Ronald Iverson, a Stanford University surgeon, "Breast reconstruction is a reconstructive and not a cosmetic procedure."

He cites a study which found that 84 percent of plastic surgeons reported up to 10 patients each who were denied insurance coverage for reconstruction of the removed breast. This could mean 40,000 cases per year. Commendably, my state has passed a law requiring coverage of breast reconstruction after a mastectomy. However,, we need a national standard, covering all insurance policies.

SECOND OPINIONS COVERED

Another important provision of our bill is insurance coverage of second opinions for all cancers. The news of possible cancer is traumatic. It is a dreaded fear that we all live with daily. For this life-threatening disease for which there is no cure, more information is better than less. Expert and balanced advice is needed to make all-important decisions. Requiring insurance plans to cover second opinions encourages people to get them and to weigh all possible options.

Patients often need specialty care. A December 1996 study reported in the New England Journal of Medicine found that specialty care improves the outcome of heart attack patients. This should come as no surprise. Specialists are knowledgeable about their field. A California doctor pointed out that non-specialists may order a "battery of unnecessary and sometimes invasive and risky examinations" for patients. Thus, incentives that discourage the use of specialists or referrals to specialists, can end up costing the insurance plan more—instead of saving money.

NO FINANCIAL INCENTIVES

Finally, out amendment prohibits insurance plans from including financial or other incentives to influence the care a doctor's provides, similar to a law passed by the California legislature last year. Many physicians have complained that insurance plans include financial bonuses or other incentives for cutting patient visits or for not referring patients to specialists. Our bill bans financial incentives linked to how a doctor provides care. Our intent is to restore medical decision-making to health care.

For example, a California physician wrote me, "Financial incentives under managed care plans often remove access to pediatric specialty care." A June 1995 report in the Journal of the National Cancer Institute cited the suit filed by the husband of a 34-year old California woman who died from colon cancer, claiming that HMO incentives encouraged her physicians not to order additional tests that could have saved her life.

Our bill tries to restore professional medical decisionmaking to medical providers, those whom we trust to take care of us. It should not take an act of Congress to guarantee good health care, but unfortunately that is where we are today.

I hope you will join us in supporting this bill, an important protection for millions of American who face the fear and the reality of cancer every day. Enough is enough. It is time for this Senate, for this Congress to send a strong message to insurance companies that we must put care back into health care. Medical decisions must be made by medical professionals, not insurance clerks.

TESTIMONY OF

CONGRESSWOMAN SUE W. KELLY (NY-19)

Mr. Chairman, Senator Rockefeller, and other members of the Subcommittee, I am Congresswoman Sue Kelly -- the primary sponsor of the House companion bill to S. 249. Thank you for having me here today; but, more importantly, thank you for holding this hearing on legislation that is of such paramount importance to the 2.6 million women living with breast cancer. I would also like to thank Senators D'Amato, Feinstein and Snowe for leading the way for this legislation in the Senate.

As all of you are aware, last month was National Breast Cancer Awareness Month. But in many families, EVERY month is Breast Cancer Awareness Month.

- Sometimes because a mother is fighting the disease:
- Sometimes because an aunt is in remission;
- Sometimes because a grandmother lost her life to breast cancer;
- Or in my case, because my sister is fighting this silent predator, which touches more than of 180,000 women each year.

Since you have already heard testimony outlining provisions of the *Women's Health and Cancer Rights Act*, I would like to focus on the need for this legislation, as well as respond to a few of the main criticisms of the bill.

I have heard some of our opponents claim that this bill is unnecessary, and that there is no problem of "drive-through" mastectomies, that coverage of reconstructive surgery is not being denied, and there are very few incorrect cancer diagnoses.

If that were the case, we would have no stories of women being released from hospitals as early as 6 hours after a mastectomy with instructions on emptying drains attached to their bodies. But we do have these stories -- horrible stories!

It is important to clarify that the *Women's Health and Cancer Rights Act* sets no arbitrary limit on a patient's length of stay. This legislation merely places that decision where it belongs -- with the physician and patient. I am more than willing to accept that, while one women might take days to recover from a radical mastectomy, another woman might adequately recover, and even be eager to leave the hospital, in only 12 hours following her surgery. The point is, a doctor should make this decision in consultation with the patient, not an insurance company bureaucrat.

I would like to share with you the experiences of one of my own constituents. Ms. Jeanette Spada of Wappingers, New York was diagnosed with breast cancer in 1985 at the age of 37. Since that time, she has had two mastectomies and was initially denied reconstructive surgery on the basis that her health care policy deemed the procedure "cosmetic." Just last month, she wrote the following:

> "I didn't realize that there was a dollar limit on my physical and mental well-being. The 'powers that be' at these Health Maintenance Organizations have to be made to realize that there are living and breathing people attached to their paperwork and we would like to remain living and breathing."

With regard to the impact of losing a breast, we must understand that nearly all breast cancer survivors feel that their self-image is at stake, at a time when their optimism and inner strength can literally be the difference between life and death. In addition, studies have documented that the fear of losing a breast and the consequent personal cost of reconstruction are leading reasons why women do not participate in early breast cancer detection programs. We could ease such fears by providing coverage of breast reconstruction.

This bill also covers second opinions for all cancer diagnoses. Up to one-fourth of all invasive breast cancers are not detected by mammography in 40- to 49-year-olds. It is unacceptable that we abandon patients, unknowingly in need, simply because of false-negative test results when a second opinion could save their life.

The experiences of the thousands of breast cancer survivors, including my own sister, have made me realize that we should have no greater priority than empowering those with breast cancer with the right and ability to play an active role in the management of their treatment. It is our obligation as leaders to ensure them that their medical treatment is in the hands of physicians, not insurance companies. It is a profound injustice when health care forgets about the patient. Yet, with regard to mastectomy recovery and breast reconstruction following a mastectomy, this is just what has been, and is, going on.

I realize that some Members of Congress, as well as a few interest groups, are opposed to the *Women's Health and Cancer Rights Act*, typifying certain provisions of the bill as mandates leading to government-controlled health care. Developing a system of health care which maximizes an individual's control over one's health care is a goal I strongly support. Furthermore, I agree that free market principles could ensure that the health care we receive is of the highest quality. However, while this is certainly a worthy goal, we are definitely not there yet. Meanwhile, how can we in Congress turn our backs on those asking for the mere right to make their own care decisions with their doctor. Currently, HMO more appropriately stands for "Healthy Members Only."

Most Americans do not have access to multiple health care plans or program options from which to choose. Until they have this choice, it will be necessary at times for Congress to enact targeted reforms -- such as the *Women's Health and Cancer Rights Act* -- that safeguard quality care while at the same time avoiding overly broad regulations and mandates. Let's face it, if a one-size-fits-all mentality does not work for government-controlled health care, why should it work for our nation's managed care organizations.

Mr. Chairman, how many casualties are we willing to witness in our movement toward market-based health care? Approximately 44,000 women will die of breast cancer this year alone; only 4,000 less than all of the American men and women killed in battle during the Vietnam War. The *Women's Health and Cancer Rights Act* aims to give women with breast cancer the opportunity to participate in the management of their treatment and the dignity to endure the fight. Please, let's empower these women.

Mary Armao McCarthy

Thank you for the opportunity to testify on an issue of so much concern to me and to thousands of other women -- the treatment of breast cancer by health plans. I am testifying today as an individual who, when confronted with breast cancer and a health plan that refused to cover medically appropriate services, fought back and won. Most women are not able to do so. In my position as Executive Director for the New York State chapter of the American College of Obstetricians and Gynecologists, I had the information to fight my insurer and, equally important, contacts with those that would help me. You see, bipartisan pressure from the leaders of the New York Legislature convinced my health plan to reverse its decision. These leaders and my organization worked together to pass legislation in New York. Of course, our bill only protects those women not insured by ERISA health plans. So, I'm delighted to be here today to help pass a national bill so that no women in the future have to go through what I did. And more importantly, so no women have to go without appropriate care, which I have no doubt is happening today.

I would like to share my experiences on three major subjects within the bill: mastectomy, reconstructive surgery, and second opinion.

I thought I was very well informed on health care issues and systems. I thought I had excellent health care coverage. **Yet my own reconstructive surgery and my second opinion were denied by my health care plan.**

My reconstructive surgery was denied in April 1996, as not medically necessary. My plastic surgeon and I worked hard through traditional means with my health care plan, and we could not secure approval. It was only through the intercession of two offices in the New York State Legislature that my health plan reversed its decision and approved my surgery. I would like to acknowledge the support of Senator Joseph Bruno, Majority Leader of the NYS Senate and Assemblyman Richard Gottfried, Chair of the NYS Assembly Health Committee. However, I am concerned that other women who do not have these resources, are accepting denials and are not receiving care.

I would like to take a moment to explain the importance of reconstructive surgery for women who choose it. My mastectomy was clinically curative, but my reconstructive surgery was emotionally healing. There is no longer a reminder every day of my cancer. When I get dressed in the morning...in an intimate moment with my husband...if I have my nightgown on at home with my children...I look normal and I feel normal.

If you lose an ear or a testicle or a part of your face to cancer, there is no question that reconstructive surgery is covered. Yet denials for breast reconstruction are serious and they are rising. In a 1996 study by the American Society of Plastic and Reconstructive Surgeons, 84% of plastic surgeons reported that they had over 10 denials for breast reconstruction for cancer patients in the previous year.

For a disease with the magnitude of cancer, it is vital to have access to second opinions and to be able to go outside your HMO, if necessary, for special expertise. To my surprise, and to the shock of my own physicians in my plan, my HMO refused to authorize my second opinion. I had a second opinion because I paid for it myself.

Not all patients have such resources...nor should they have to. During the high physical and emotional stress of cancer diagnosis and treatment, access to a second opinion must be a routine, required insurance benefit.

The number of outpatient mastectomies, nationwide, has increased from 1.6% in 1991 to 7.6% in 1995. My particular cancer required a mastectomy. I was in the hospital for five days. In New York State, the average in-patient hospitalization for mastectomy is 4.2 days. It is critical that appropriate length of stay be provided.

I am very concerned by initial comments made by some representatives of HMOs that women could go home after an outpatient procedure and that their care could be assumed by family members. No family should be forced to assume this kind of responsibility. When I was in the hospital after my surgery, a nurse assigned to my care actually cringed and looked upset when my doctor changed my dressing. A mastectomy is an amputation. I spoke candidly to my husband, who goes with me to most of my medical appointments, and he felt that he could not have handled the emotional or the clinical responsibility of helping with drains and bandages. An appropriate length of stay must be protected.

I am pleased to report that the provisions contained in the Health and Cancer Rights Act are now law in New York State. I applaud the leadership of Senator Al D'Amato and the work of the New York State Legislature and Governor George Pataki in this important achievement. Regrettably, it is estimated that over half of the women in New York State are not protected by our law, due to the ERISA exemption. Federal legislation is needed to cover the self-insured plans and to extend the benefits of this law across the nation.

I am concerned and frightened about the trend we are experiencing of reducing health care services for women. Recently, as you recall, it was maternity stays. Now it is breast cancer services. Where will it end?

Over the long term, we need comprehensive legislation to ensure that valid medical standards are used for all medical conditions and procedures.

Again, to protect women, federal legislation needs to be enacted and needs to be enacted now. I want to praise Senator D'Amato for the leadership that he has shown and express my gratitude for his assistance during my turmoil. I am pleased to report that Senator D'Amato's bill has been endorsed by the American College of Obstetricians and Gynecologists. I understand that there are also bills introduced by Democratic Senators and endorsed by the President. In New York, we were able to protect women because Democrats and Republicans worked together. I hope that I will be able to say the same for the U.S. Congress next year.

Thank you for the opportunity to testify. I would be happy to answer any questions that you may have.

Senate Finance Committee
November 5, 1997
Lillie Shockney, R.N., B.S., M.A.S.

I have worked at the **Johns Hopkins Hospital** for the past 15 years. For the last decade I have functioned in the capacity of **Director of Performance Improvement and Utilization Management.** My responsibilities included measuring and assessing quality of care and ensuring the care provided is medically necessary and appropriately delivered at the right level of care. Beginning in July of this year (1997) I chose to transfer from this director's position to assume a new director's position in the Johns Hopkins Breast Center. **I am now the Education and Outreach Director of the Johns Hopkins Breast Center.** In this role I function as the **patient advocate,** am responsible for our performance improvement program, patient education program, survivorship program, outreach activities, and oversee our breast cancer survivor volunteer program. **My educational background includes an RN degree, a BS in Health Care Administration and a Master's degree in Administrative Science from the Johns Hopkins University.**

I also have a fourth degree that doesn't appear on my business cards but it is the degree that was hardest to earn and the one I take the most pride in — that is my C.S. degree— my "cancer survivor" degree. **I was diagnosed with breast cancer at the age of 38 in July 1992 and underwent a left sided modified radical mastectomy. Since that time I have had a lumpectomy of my right breast in July 1993 and finally a right sided mastectomy in July 1994.**

I am also the **co-founder and Vice President of a national non-profit organization** called "Mothers Supporting Daughters with Breast Cancer", designed to provide emotional support to women battling this disease and their mothers who are very worried about them and want to be involved in their daughter's care and recovery.

I am a Reach to Recovery **volunteer** for the American Cancer Society and see and speak with newly diagnosed patients every day. I also do volunteer work for the Susan G. Komen Foundation, Y-ME, and other breast cancer organizations locally, regionally and nationally. I'm a published author on the subject of breast cancer, having written two books about my personal experiences with breast cancer and many articles all of which have been published.

As a result of my personal experiences with breast cancer, my clinical background which includes providing care to women with breast cancer, and my quality of care and utilization management experience, I feel that I am in a good position to offer opinion about proposed state and federal bills related to breast cancer diagnosis and treatment. My personal and professional mission is to do whatever I can to continuously improve care for women who become diagnosed in the future...the future beginning with today.

Since 1994, I have been speaking across the country about breast cancer, the need for promoting mammograms and self breast exams, the value of humor as complementary therapy, and the need to develop national quality standards for breast cancer diagnosis and for promoting mammograms and self breast exams, the value of humor as complementary therapy, and the need to develop national quality standards for breast cancer diagnosis and treatment. Just in the last 6 weeks I have given more than twenty speeches across the country. As I travel from state to state I am exposed to breast cancer survivors who candidly share their personal stories with me. These stories have confirmed for me that we have a wide variation in the quality of care that women are receiving who have and are battling this disease. There are some hospitals and doctors who are still performing mastectomies the way they were done 30 years ago. There are some hospitals and doctors who have chosen to seek out ways to improve care and treatment and as a result make breast cancer surgery less traumatic for their patients; we need all hospitals to do so however.

Though I believe that this bill under consideration today is a dramatic improvement over the bills previously considered that recommended a specific length of stay for patients having a mastectomy or lumpectomy with lymph node removal, I am concerned that it doesn't solve the real medical dilemma that women battling breast cancer are faced with today. We need to be striving to improve patient care for patients undergoing breast cancer surgery rather than unknowingly promote keeping it at status quo. The wide variations in patient's personal stories reaffirms for me that the time has come to address this issue as the real issue. Women should be able to feel confident they are receiving the best care they can get no matter where they are seeking it. There are variations in the degree to which a patient is empowered with information. We need to be promoting the development of a comprehensive patient education program and have teams of health care professionals dedicated to striving to improve the care and treatment provided to women with breast cancer. This bill doesn't seem to address that need. We will therefore see some patients staying in the hospital for 1 day and other potentially staying in for 10 days, both having had the exact same surgical procedure. We have failed to define what is the "best care."

In order for women to be able to participate in the decisions about their length of stay they need to be educated about their disease, treatment options, and directly participate in the decisions about their care as an active partner of the health care team. This bill doesn't enforce the need for patient education and as a result patients may choose to stay in the hospital for an extended period of time due to lack of knowledge. One risk of extended hospital stays is exposure to germs that can cause infections. Patients with drains are more likely to develop an infection by staying in the hospital than some other patients. The tendency for the patient and the doctor might be to keep the patient in the hospital until her drains are removed which could take on average 10 to 12 days or longer. This will not result in better care for the patient. It could discourage health care professionals from taking the time to develop and incorporate as part of the patient's care a comprehensive patient education program that empowers the patient to make good decisions with the assistance of her doctors and nurses.

Johns Hopkins made a conscious decision to begin performing mastectomy surgery on an outpatient basis because it hypothesized that it would result in better quality of care... and for us it has. The initial recommendation to convert the surgery to outpatient surgery was made by **a patient.** The Johns Hopkins Breast Center continuously strives to identify ways to further improve care for its patients and the source that we use for identifying what needs to be improved comes from listening to our patients. The faculty base **all** of their changes in treatment modalities on input and advice from **the patients** combined with whatever is state of the art technology and treatment currently available. Because I have undergone three breast cancer operations within a three year period, I have had the unique opportunity to personally experience the steady improvements made by the health care professionals there.

Johns Hopkins **did not** convert the majority of its mastectomy care to an outpatient setting due to pressure from managed care. On the contrary, Hopkins began doing this procedure as outpatient surgery even before the UR guidelines written by Milliman and Robertson, which are utilized by managed care organizations, were changed to recommend that it be an outpatient procedure. I'd like to emphasize that to date we continue to have no pressure from managed care organizations about outpatient mastectomy surgery. We changed because we thought that by providing a comprehensive patient education program from the onset when the woman is initially diagnosed, getting her family involved, and most importantly empowering the patient so that she can directly participate in the decision making about her care and treatment, she would do better physically and emotionally, short term and long term. Based on feedback obtained from our quality of care patient satisfaction surveys this theory we believe was and is right, though we by no means no if the care we are providing is truly ideal. This requires a formal clinical study to determine if that is our actual outcome.

When we assessed the care we were providing to women having breast cancer surgery and seriously looked at what was the primary reason the patient needed to be hospitalized it was usually due to nausea and vomiting and pain. We learned that if we could control the nausea and vomiting we could prevent the patient from having much physical discomfort. By making changes in the anesthesia management of the patient combined with reducing the amount of time the patient is sedated and administering a specific anti-nausea drug and other medications during the operation, we prevented the medical reasons for having to have the patient spend the night in a hospital bed.

If we have done our job well, which includes preparing the patient and her family by taking them through a "dress rehearsal" several days prior to her surgery, and performed the surgical and anesthesia management as described above, then the most important need the woman has the evening of her surgery is emotional support. This is best provided in the privacy of her own home or even a hotel by her own family and friends.. But not in a hospital by nurses who never knew her before.

The program that is in place at Hopkins includes a comprehensive patient education program that is provided to the patient and her care partner (i.e., spouse, sister) several days prior to surgery. Patients are also connected up with a breast cancer survivor who has had the same type of surgery, is about the same age, and other similar backgrounds to help answer questions that can only be really addressed by someone who has experienced the same thing. This emotional support offered by survivors begins as soon as the patient is diagnosed. The surgical procedure itself, is done in approximately 45-50 minutes, the anesthesia management includes preventive care for nausea and vomiting. The patient also receives a minimum of two home health visits by nurses specially trained by the Johns Hopkins Breast Center staff in wound care and drain management, and psychological assessment for mastectomy patients. Initially we experienced some problems with managed care organizations not being willing to pay for these two home health care visits. But rather than calling my congressman or senator, I invited the managed care organizations and the home health care agencies into the hospital for a free half day seminar on ambulatory surgery mastectomy. After managed care organizations were educated about the value of the home health care visits we no longer experienced problems with reimbursement for this portion of the patient's care. (Again, education was the key.) As part of the program at Hopkins, patients can also reach their doctor or breast center nurse 24 hours a day , 7 days a week through our special urgent care program that is in place but rarely needed. Most patients go home with a prescription for oral narcotic pain medications but only usually take plain Tylenol.

The physicians (surgeon and anesthesiologist) determine if the patient is a good candidate for having her surgery done as an outpatient. The ultimate decision to have her surgery as an outpatient rests with **the patient. It is the patient's choice**. The patient can even change her mind in the recovery room and decide to be admitted over night but this is truly a rare occurrence. In 1996, between 65% and 70% of our patients undergoing mastectomy without reconstruction chose to have their surgery done in this way. For calendar year 1997, thus far, the statistics show that 81% of our patients are opting for this approach. We are also seeing patients returning to work sooner than traditionally in the past. Their satisfactions scores reaffirm that we are doing the right thing on behalf of our patients.

Last year at this time there was considerable discussion in the media and in committee sessions like this one today about mandating that managed care organizations pay for at least a 48 hour hospitalization for women undergoing mastectomy surgery and a 24 hour hospitalization for women undergoing lumpectomy surgery with lymph node dissection. I expressed my concerns at that time about such a bill being considered in Maryland because I feared that it would discourage hospitals and health care professionals involved with breast cancer patients from taking the initiative to improve patient care— in essence, work to eliminate the occurrence of nausea and vomiting post-operatively, have patients well prepared for what to expect including the management of their drains after surgery, empower women to be well educated about this disease and the treatment options available to the patient so she can be a member of her own health care team and feel confident in the treatment plan chosen. I also learned quickly that people were confused about which types of breast cancer surgeries this bill was intended to cover. There were many women who I heard testify who had had a mastectomy **with** simultaneous reconstruction for which it is medically necessary for such patients to be hospitalized. There was also an outcry from women that the reason why the patient needed to stay in the hospital was "due to having drains in." Well, patient's drains stay in for 4 days to 30 days with the average being about 10-12 days. So **regulations keeping the patient in the hospital for 48 hours had nothing to do with**

women's concerns about drains. It did point out that there was little patient education about drains and what to expect post-operatively being explained pre-operatively... another sign of a need to improve patient care.

I recognize that this particular bill for consideration today is different than those that have been presented before. Rather than mandating a specific length of time for hospitalization, it would be left up to the doctor and the patient. I very much like the concept of leaving the decision to the doctor and the patient. Though at first blush this can sound like a good idea, in the long run I don't think that we will be doing justice for women battling this disease. That is because such a bill would actually discourage health care providers from developing improvements in surgical management that women deserve. We run a risk of having women continue to be hospitalized for several days due to nausea and vomiting and pain— rather than having prevented these symptoms from the onset. We run a real risk of patients staying hospitalized until their drains are removed which will increase the risk of the patient developing a hospital acquired infection as was the case 30 years ago when women stayed in the hospital until the drains were removed.

Let's focus on developing ways to improve patient care rather than allow care to continue "as is" and pay for mediocre quality. We need to conduct formal clinical studies that can compare the variations in surgical management that women are experiencing in this country and define what is the "ideal", then mandate that this be the standard of care and treatment all women can expect to receive. To date no such studies have been done. We did approach Milliman and Robertson about providing a grant to fund such a study that could be conducted at six well known comprehensive cancer centers here in the United States. We had even gone ahead and approached these other cancer centers and got commitment from them to participate. Leadership at Milliman and Robertson recently said they were not interested since they thought people were no longer concerned about mastectomy length of stay.

A good analogy for looking at dramatic improvements in surgical management of a specific medical problem is gallbladder surgery. If you speak to someone who had their gallbladder out 20 years ago you will hear a patient describe a horrific experience. Hospitalized for 10 days, on morphine for severe pain, nine inch incision across his abdomen, nasogastric tube down his nose and stomach and "the worse pain I've ever felt in my life", and unable to return to work for another six to eight weeks. If you talk to someone who had their gallbladder out this year you will get a very different story. The individual will probably say that the procedure was done as an outpatient, incision only one inch long, virtually no pain, no drains or tubes, and back to work in less than a week. Why are the stories so dramatically different? Because of improvements in surgical and anesthesia management for gallbladder disease. The same dramatic improvements are now possible for women undergoing breast cancer surgery, but it requires an investment in time and resources by health care professionals and hospitals who take care of women with this disease. Perhaps it also requires an investment of money for such clinical studies to be undertaken with funding coming from managed care and organizations such as Milliman and Robertson or by the federal government.

If we say that the patient can stay in the hospital as long as the doctor and patient wishes then we run a risk of propelling ourselves backwards in time rather than making improvements in treatment. We may discourage patients from becoming empowered and actively participating in their own care. We might rely on health care professionals for emotional support when we should be primarily working with the family and survivor volunteers to help with this aspect of care. From a severity of illness perspective women who undergo mastectomy without reconstruction are going to be the least ill on an inpatient nursing unit. This means that the nurses and doctors have to spend much of their time with other patients who are critically ill. There is a lack of time for health care staff as a result to attempt to address the emotional needs of the breast cancer patient.

So I'd like this portion of the bill being considered today to be rethought. Though I know the intentions are good, the outcome may not yield at all what is intended. So rather than developing regulations regarding length of stay for breast cancer surgery, lets work together to define the ideal patient experience for breast cancer surgery. Women deserve the best care they can receive. We need to make the surgical treatment of breast cancer as least traumatic as possible. Keeping the patient hospitalized for some extended period of time will not address this need. Comparing various surgical treatment plans and working with patients and health care providers to define "best practice" is the direction I'd like to see us go. Promoting the potential for overutilization of hospital resources and a continuation of the "same old surgical treatment plan" will not be of benefit to women diagnosed in the future.

As I have traveled across the country I make a point of talking to breast cancer survivors about their thoughts regarding national quality standards. It is not uncommon for me to receive a standing ovation when I discuss this topic. When I discuss the Johns Hopkins ambulatory surgery mastectomy program, breast cancer survivors in the audience often times say to me that if they had been prepared in advance about their drains, if they had been educated about their disease and its treatment, and if they had been treated like part of their own health care team they would have had a better emotional and physical recovery. I think they are absolutely right. We don't believe that we have yet developed the ideal patient experience but we hope we are on the right track. So let's turn the burners up on promoting improvements in patient care. Let's not leave a wide open door for letting care remain the way it is...

Women's Health & Cancer Rights Act of 1997

Statement of U.S. Senator Olympia Snowe
Before the Senate Finance Committee
November 5, 1997

Mr. Chairman. I would like to applaud you for your leadership in convening this important hearing on the Women's Health and Cancer Rights Act. It is under your guidance, and that of Chairman Roth, that this Committee is tackling some of the most difficult issues facing our health care system today. I would also like to commend my colleagues, Senator D'Amato and Senator Feinstein, for their leadership on this critical legislation.

This bill is about doing what's best for women facing the crisis of a cancer diagnosis and a potential mastectomy. Because the fact is, right now, some women are being denied the best health care available. The bottom line is: that's not acceptable in a country of such vast medical resources. We can do better, and we *must* do better.

This year, millions of Americans will face the possibility of a cancer diagnosis, and 180,000 women will be diagnosed with breast cancer. In 1992, an estimated 73,000 women underwent a mastectomy, and almost 30,000 had reconstructive surgery. Our bill provides women with breast cancer and all Americans facing a cancer diagnosis with crucial protections that are needed in a health care market that is increasingly dominated by managed care.

First, it ensures that doctors are not pressured by health plans to release mastectomy patients before it is medically appropriate. Currently, some insurers have guidelines recommending that mastectomies be performed on an outpatient basis. In fact, a *New York Times* article earlier this year reported that approximately eight percent of all mastectomies are performed on an outpatient basis. Yet many doctors advocate a longer stay -- in fact, the average stay in New York is 3.6 days.

This decision must be returned to physicians and their patients. The physical scars left by a mastectomy can be complicated and difficult to care for, and often require supervision. Women prematurely released may not have the information they need, and some dangerous complications can arise hours after the operation. And all of this is happening in context of the intense emotional trauma that comes with losing part or all of a breast.

Second, the bill requires insurance companies to cover breast reconstruction following cancer surgery, as well as surgery to make breasts symmetrical. I am proud that this provision is based on a law now in effect in my own state of Maine. But unfortunately, this state law is not enough. Although my constituent, Bonnie Bishop, lives in a state that has an excellent reconstructive surgery law on the books, her employer self-insures. As a result, she has been denied coverage of the reconstructive surgery that would provide her with physical relief and restore a feeling of "wholeness" to her life on the grounds that it is not medically necessary.

Unfortunately, Bonnie is not alone. A recent survey found that 43 percent of breast cancer survivors had been denied coverage for follow-up reconstructive symmetry procedures.

Mr. Chairman, insurers cover reconstructive surgery for other body parts affected by cancer. Yet today, many companies deny coverage of breast reconstruction because they deem it "cosmetic". They are wrong. The procedure can help repair the physical as well as psychological scars, allowing breast cancer victims to forge ahead with their lives.

This double-standard in coverage is wrong and the D'Amato bill puts a stop to it. Studies show that the fear of losing a breast is a leading reason why women do not participate in early breast cancer detection programs. If women understand that breast reconstruction is widely available, more might participate in detection programs that can save their lives.

Finally, all Americans who face the possibility of a cancer diagnosis must be able to make informed decisions about appropriate medical care ...about their future. To do that, they need access to all the information available.

A second opinion can mean the difference between life and death. Our bill requires insurance companies to pay full coverage for secondary consultations with a specialist whenever any cancer has been diagnosed or a treatment recommended. This will reduce senseless deaths resulting from false diagnoses and empower individuals to seek the most appropriate available treatment.

Women with breast cancer and all Americans facing a cancer diagnosis should not be forced to wait any longer for these important protections. They deserve swift action on this important bill.

NATIONAL BREAST CANCER COALITION

• a grassroots advocacy effort •

Testimony of Frances M. Visco, Esq.
President, National Breast Cancer Coalition

before the

Senate Finance Subcommittee on Health Care

November 5, 1997

Thank you, Mr. Chairman and members of the Finance Subcommittee on Health Care. I am Fran Visco, a breast cancer survivor, a wife and mother, a lawyer and President of the National Breast Cancer Coalition (NBCC).

The NBCC is a grassroots advocacy organization dedicated to the eradication of breast cancer through action and advocacy. It is made up of over 400 member organizations and tens of thousands of individuals. The NBCC seeks to increase the influence of breast cancer survivors and other activists over research, clinical trials, and public policy and to ensure access to quality health care for all women.

As a breast cancer activist, I am committed to doing my best to ensure access to effective, quality health care for those women with this disease. As we examine the issues surrounding quality health care, it is important for this Committee to keep the reality of this disease in perspective. We still do not know the cause or have a cure for breast cancer. Today, there are 2.6 million women living with breast cancer. This year alone, more than 184,000 women will be diagnosed with breast cancer and 44,000 will die of the disease. It is only through encouraging increased research and incorporating the use of evidence-based science and new technology in treating patients that we will move closer to finding the best care for breast cancer and eventually prevention and a cure.

On behalf of the National Breast Cancer Coalition members across the nation, I applaud the Congressional sponsors and supporters of the Women's Health and Cancer Rights Act of 1997, as well as the sponsors and supporters of additional pending legislation which also addresses these issues. This legislation is an important step in realizing NBCC's goal of ensuring that women have access to the health care they need. This legislation will put a stop to the practice of insurance companies allowing cost and not medical evidence to determine when a woman leaves a hospital after breast cancer surgery, will make certain that no insured woman is denied coverage for reconstructive surgery, and will ensure that coverage is provided for a second medical opinion.

As we focus today on quality health care, we cannot forget the millions of women living in the U.S. who do not have health insurance; their struggle to get the health care they desperately need will not be met by the proposal this Committee is considering. There is a need for this legislation because this nation lacked the courage to reform meaningfully our health care system by providing universal coverage and quality care to women and their families. As a result, market forces are now propelling the changes in the health care system and women are at risk of being forced to pay the price by having inappropriate limits placed on their access to quality health care. We realize disease specific legislation is not the most efficient or productive way to create effective public policy, but until guaranteed access to quality health care coverage and service is available for women and their families, there are some very serious patient concerns that must be met. The NBCC is still committed to universal access to quality care, but while we fight for that goal this legislation helps alleviate some of the worst shortcomings of our current system. We are aware of pending legislation which will reform the health care system and the NBCC intends to work with key legislators to ensure that the best possible bill is passed.

The ability of insurance companies to reduce significantly minimum standard of care for breast cancer patients is one such shortcoming. The NBCC believes that to ensure access to quality care for breast cancer treatment for all women, legislation must include at least the following four provisions: 1)guarantee that the length of stay in a hospital after breast cancer treatment is determined by individual medical needs based on an appropriate level of evidence, not by the insurance industry; 2)breast reconstruction surgery should be covered by insurance after a mastectomy; 3)insurance coverage should be provided for breast cancer patients to obtain a second professional opinion; 4)a strong consumer protection provision should be included to ensure the breast cancer patients' interests are not compromised in any way.

When women are faced with the trauma of breast cancer surgery, it is essential that the length of their hospital stay be determined by personal medical necessity, not economics. While it is true that some patients are able to receive the pre-operative education needed to have a successful outpatient mastectomy, this option is not necessarily the best for all women.

We believe strongly that breast reconstruction should be covered by insurance. To suggest that breast reconstruction after a mastectomy is cosmetic surgery and should not be covered by insurance, which some plans currently claim, is simply ludicrous. Patients in need of prostheses for other body parts do not endure the shameful suggestion that their prosthesis is cosmetic, nor should breast cancer survivors. Breast reconstruction can be an essential step in the follow-up treatment for a breast cancer survivor. Although not all women opt for reconstruction, or to use external prosthesis, those who do must not be denied the essential follow-up treatment they need.

In addition, the options for follow-up reconstruction care should not be dictated by an insurance provider. There are some insurance plans that cover reconstructive surgery, but not external prosthesis. Other plans only cover certain types of reconstructive surgery, generally the less expensive surgery. Further, some plans place a time limit on insurance coverage for reconstructive surgery, forcing a woman to make a decision she may not be comfortable with or leaving her to regret her decision down the road. This practice is disgraceful. Women should have access to and be covered for the best type of surgery and follow-up treatment according to their individual and personal needs as decided by the patient and physician, within reason.

When dealing with the life threatening reality of breast cancer, it is also essential that a woman be given the opportunity to seek a second professional opinion. These are life-changing events and a patient must have the option to seek a second opinion to gain confidence in the care they will receive. An insurance plan must either have enough physicians that a patient is able to go to another doctor in that plan, or the patient must be allowed to go outside of the plan for the second opinion. Insurance coverage for this service is a step towards guaranteeing patients access to genuine quality health care.

In addition to providing specific treatment provisions, legislation guaranteeing access to quality health care for women and breast cancer patients must also include strong consumer protections. These protections are essential in ensuring women do in fact receive the highest quality care for the treatment of breast cancer. In addition to the protections in S. 249, NBCC recommends including language which prohibits an insurance plan from unfairly denying women coverage or eligibility for the purposes of avoiding the previously discussed requirements; and prohibits plans from providing monetary payments to encourage patients to accept less than the minimum protections. Furthermore, there should be language included which prohibits the insurance plan from penalizing physicians for providing the required care or provides incentives to physicians to induce less care than required. Consumer protection language will help to guarantee access to quality health care in all aspects of breast cancer treatment.

In conclusion, I commend the Committee for holding this hearing and seizing the opportunity to rectify the emerging issues that adversely affect women and their families while Congress restructures the health care system. We offer thanks to Senator D'Amato, all of the supporters of the Women's Health and Cancer Rights Act, as well as the sponsors and supporters of similar legislation which addresses the same issues. We look forward to continuing to work together to ensure women with breast cancer get the best treatment available now and in the future. Thank you again for inviting me to testify and giving hope to the 2.6 million women living with breast cancer.

PROJECT HOPE
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Center for Health Affairs

Women's Health And Cancer Rights Act of 1997

TESTIMONY

Presented to

Subcommittee on Health Care
Senate Finance Committee
U.S. Senate

By

Gail R. Wilensky, Ph.D.
John M. Olin Senior Fellow
Project HOPE
on

November 5, 1997

Thank you Mr. Chairman for inviting me to appear before the Subcommittee on Health Care of the Senate Finance Committee to provide testimony regarding S. 249, the "Women's Health and Cancer Rights Act of 1997." My name is Gail Wilensky and I am the John M. Olin Senior Fellow at Project HOPE, an international health education foundation. I am also the chair of the Medicare Payment Advisory Commission and a former Administrator of the Health Care Financing Administration. However, I am here today only as someone with expertise in health care policy and financing. My views are my own and do not necessarily reflect those of my affiliated institutions.

BILL PROVISIONS

Under S. 249, all private insurance would: 1) require coverage of an inpatient stay for women undergoing breast cancer surgery (mastectomy, lumpectomy or a lymph node dissection) for an unspecified length-of-time, to be determined based on the physician's assessment of medical necessity; 2) require coverage for reconstructive surgery on the diseased and non-diseased breast, if deemed by the physician and patient; and 3) require coverage for a second opinion to be provided by a cancer specialist, at no increased cost to the patient.

Breast cancer and breast cancer surgery are deeply emotional issues. About 182,000 women will get breast cancer this year, and more than 110,000 mastectomies will be performed this year. It is easy to understand the sympathy this issue raises. However, it is not at all clear that there is a problem involving breast cancer coverage that requires new Federal legislation and proposing new Federal mandates on private health insurance coverage (including ERISA-exempted health and welfare plans) raises a series of concerns: concerns about the role of the Federal government in areas that traditionally have been under the domain of the states, the impact of mandates on the cost of health care and the impact of mandates on locking-in standards of care that exist at a given point in time.

MISMATCH BETWEEN PROBLEM AND SOLUTION

About one year ago, an article appeared in the Hartford Courant, with follow-up stories in the Washington Post and Wall Street Journal suggesting that two Connecticut HMO's were requiring physicians to perform some mastectomies on an outpatient basis and not covering an overnight hospital stay unless it was stated as medically necessary by the physician. This led to charges that managed health care plans are limiting coverage for mastectomies to outpatient treatment and in other ways, negatively effecting the treatment of breast cancer surgery for financial reasons.

The empirical evidence that exists, however, suggests that the rate of outpatient mastectomies remains relatively small and that the rates between HMO's, other managed care and fee-for service are comparable or at least not higher for managed care. For example, according to the New York Department of Health, Bureau of Quality Management and Outcome Research, of the 7016 mastectomies performed in 1995, only 124 were performed on an outpatient basis and of these only 19 were in HMO's. Among the 74 performed on the Medicare population, 72 were financed by traditional Medicare and 2 were covered by Medicare HMO's. Similar statistics were reported by HCIA, a Baltimore-based health information company, for Medicare beneficiaries in 1996. Only 7.6% of the Medicare beneficiaries having mastectomies were treated on an outpatient basis and the vast majority were covered under traditional Medicare.

The MEDSTAT Group, a health care data analysis firm, analyzed records from their database of privately insured employees between 1993 and 1994, and found that there were generally consistent rates of mastectomies performed on an outpatient basis across insurance groups. The only significant differences were that fee for service plans had the highest rate of outpatient procedures for simple mastectomies (26% versus 17% for HMO's and 11% for PPO/POS) and that PPO's/POS had the highest rate for modified radical and radical mastectomies (12% versus 5% for HMO's and 9% for FFS plans).

MANDATES HAVE UNDESIRABLE CONSEQUENCES

Aside from the philosophical issue of expanding the role of the Federal government in areas traditionally under the jurisdiction of the states, mandated benefit laws have several other undesirable and unintended consequences.

The most frequently raised concern, whenever mandated benefits are discussed, is that mandated benefits raise the cost of health care and therefore raise the cost of health insurance. This effect is particularly problematic for the almost 40 million uninsured. The states have enacted many mandated benefits over the years, exacerbating the problems of the uninsured to the point where some states have allowed for reduced benefit packages to be offered on a demonstration basis to certain groups of uninsured individuals.

In a recent report by the General Accounting Office, it was estimated that mandated benefit laws account for about 12 percent of the claim costs in Virginia and 22% of the claims cost in Maryland. The Congressional Budget Office estimated that the 1996 Federal law mandating private insurers to cover 48-hour maternity stays will cost the government $223 million over four years and that the private sector direct costs will increase by over $745 million over four years.

Government established benefit mandates also tend to lock-in standards of care that exist at a certain point in time. This means that mandated benefits, while well-intentioned, can mean making what is common practice in one period, a "requirement" in another period, particularly from the patient's point of view, whether or not it represents the latest or best in medical practice. This sense of entitlement to a service, particularly one that the patient does not pay for directly, has been particularly problematic for Medicare's home care benefit, even though it too is determined only by the patient's physician.

Mandated benefit laws do not prohibit medical progress directly but they can impede the progress that is occurring in the medical community and in the marketplace to find ways to deliver care in new, better and cheaper ways. There are several studies, for example, that show that women who meet certain medical criteria and who have certain social support systems can do far better with outpatient mastectomies. While this legislation does not prohibit outpatient mastectomy, it's requirement for inpatient coverage leads to the expectation that inpatient coverage is the norm.

Lillie Shockney, who is also testifying on this panel, can describe the successes of the Johns Hopkins outpatient mastectomy program far more accurately and eloquently than I but a few statistics are worth noting. The Hopkins Breast Center, which has gradually eliminated hospital stays for women meeting certain criteria, has reported lower infection rates and higher satisfaction among these women. A 1996 study of 525 women who underwent outpatient mastectomies at Henry Ford Hospital in Michigan reported accelerated physical recovery, earlier return to o cupational activities and numerous psychological advantages. A 1995 study at the New Jersey College of Medicine of 133 women who underwent outpatient partial mastectomies with lymph node removal and 45 women who had surgery on an inpatient basis showed the outpatient group had a lower rate of post operative infection and a higher level of satisfaction. Similar findings have by the Comprehensive Breast Care Center in Florida on a 1993 study of 221 women.

The evolution and change in health care delivery that has occurred and is continuing to occur will not be helped by Federal legislation which presumes or implies particular sites for care or particular types of treatment of care.

CONCLUDING COMMENTS

It has only been in the last decade that the medical community has focused on the need for more information on clinical effectiveness and outcomes. Many medical practices have come into use without adequate evidence of their clinical effectiveness or the circumstances limiting their effectiveness. Wide variations in medical practices for similar conditions, even after adjusting for differences in patient characteristics and illness levels, continue to be reported, including in areas of breast cancer surgery.

The Federal government has a role in funding research in these areas and in helping to disseminate the information to clinicians and patients alike. This has been area of concern for some of the centers within the NIH and a primary concern for the Agency for Health Care Policy and Research and other parts of HHS but more can and should be done.

Patients also need to understand that physicians, hospitals and health care plans differ in terms of the quality of medical care provided and the satisfaction of the patients they serve. Seeking out this information and making use of it will put important pressure on the health care system to change in ways that will improve both quality and satisfaction.

Finally, many of the problems frustrating consumers most about their health insurance coverage would disappear if they had a more active role in choosing their health insurance. Most of us have health insurance through our employers because of the tax subsidies associated with employer sponsored insurance. Some of us have many choices, particularly those working for the Federal government, the state of California and some large employers but many of us have little choice. The Kassebaum-Kennedy legislation (The Health Insurance Portability Act) passed in the 104th Congress allows the self-employed and single proprietors to deduct the premiums they pay for insurance, thus opening up the tax subsidy to a new group of the employed who will have substantial choice in the type of insurance they purchase. The Dole-Packwood legislation proposed in the 104th Congress would have allowed small employers to buy into the Federal Employees Health Care Plan on a non-subsidized basis, thus potentially opening up a wide range of choices to employees of small firms. Expanding the ways in which employees can make use of the existing tax subsidy for employer sponsored insurance would allow patients and families to exert far greater control on the type of insurance they purchase and drive the health care system to be more responsive to their desires. The Congress has taken some steps in this direction. It needs to do more.

COMMUNICATIONS

STATEMENT OF THE AMERICAN ASSOCIATION OF HEALTH PLANS

The American Association of Health Plans (AAHP) is the principal national trade association representing HMOs, PPOs, and other network-based health plans throughout the United States. The Association represents approximately 1,000 member plans serving over 140 million Americans. AAHP and its members are dedicated to a philosophy of care that puts patients first by providing coordinated and comprehensive health care.

AAHP is proud of the leadership role it has taken in addressing consumers' and physicians' concerns through its *Putting Patients First* initiative. This proactive, multi-phase initiative is designed with three goals in mind: (1) to communicate the facts about how health plans work for the benefit of patients; (2) to make it clear that AAHP and its member plans are listening to the concerns of consumers and physicians; and (3) to provide a mechanism for AAHP member plans to demonstrate their commitment to high standards of care and accountability.

AAHP appreciates the opportunity to provide its statement on S. 249, the "Women's Health and Cancer Rights Act of 1997" for the record. The topic of this hearing points to one of the many challenges Congress has before it -- how to address consumer needs for high-quality, affordable health care, and in this case breast cancer care, while at the same time promoting continued innovation and competition in the health care market.

Our statement will focus on:

- An overall context in which to consider the appropriate role of the federal government in health care;
- An assessment of the facts regarding breast cancer care of women in health plans; and

The impact of S. 249 on the delivery of quality breast cancer care services.

I. Considering the Context Before Acting

There are a number of legislative proposals pending in both chambers that would add to the current regulatory framework governing health plans. The stated intent of these proposals is to protect consumers against unfair or harmful practices. AAHP and our member plans share the goal of protecting patients. However, we believe that before Congress acts, it should consider the existing regulatory structure and the reasons our health care system has had to change over the past decade.

A. The Current Regulatory Structure for Health Plans

As a first step, it is important for Congress to survey the current regulatory structure for health plans, taking into account both public sector and private sector activities. Otherwise, it risks enacting duplicative or conflicting regulation that increases consumers' out-of-pocket costs, adds to the number of uninsured American workers, and demands that resources be shifted to administrative overhead, while *detracting* from plans' ability to focus on quality.

Today, there are multiple mechanisms already in place to promote high quality care and health plan accountability. Some of these mechanisms have been developed by the plans themselves, others are products of federal and state regulation, and still others are the result of actions taken by consumers and purchasers. Taken together, these elements have a significant impact. Already, they hold health plans to standards of quality and accountability never demanded in the old fee-for-service system. As a result, health plans have given consumers, for the first time, an opportunity to make choices about their health coverage that are grounded in meaningful information. Some of these initiatives are briefly highlighted below.

State Licensure

To be state licensed, health plans must meet comprehensive consumer protection standards established at the state level, including standards addressing areas such as quality and accessibility of services, member information, financial solvency, utilization review, and appeal and grievance procedures.

For instance, in the area of quality, the National Association of Insurance Commissioners' Model HMO Act, which is representative of state HMO acts, includes standards that are directly relevant to several of the issues raised in S. 249. The NAIC Model requires that HMOs have ongoing quality assurance programs to monitor and evaluate health services; procedures to ensure health care delivery under reasonable quality standards, consistent with recognized medical practice standards; ongoing, focused activities to evaluate health care services; and written plans for taking corrective actions as appropriate. These are just a few of the many standards for state licensure, and they typically are supplemented by detailed regulation and site visits by the appropriate state agency. As you know, we frequently discussed the importance of these standards during the debate over accountability for provider-sponsored organizations participating in Medicare.

Federal HMO Act and Federal Program Standards

In addition to meeting extensive state standards, federally qualified HMOs and health plans participating in federal programs must meet detailed federal standards under the Federal HMO Act, Medicare and Medicaid participation requirements, the Federal Employees Health Benefit Program (FEHBP), and other programs. These standards, too, address several of the issues raised by S. 249.

- The HMO Act of 1973. The Federal HMO Act of 1973 and the regulations issued under it require each federally qualified HMO to have a rigorous quality assurance program with an emphasis on health outcomes in which medical professionals conduct regular reviews of the health care delivery process and assess patient outcomes. Systematic data collection and data interpretation are a mandatory element of the quality assurance program. HMOs must have written procedures for remedial action and implement changes as necessary to maintain high quality. The HMO Act also requires plans to use written guidelines for choosing physicians.

- Medicare+Choice Program. Plans serving as Medicare+Choice organizations must meet additional standards. For instance, Medicare+Choice plans must have an agreement with an independent quality review and improvement organization to perform functions such as quality review, review for appropriateness of care, adequacy of access, and review of complaints about poor quality of care. Medicare+Choice organizations also must report HEDIS data, which will be made available to all Medicare beneficiaries. Currently, no comparable data is available to Medicare beneficiaries remaining in the old fee-for-service program.

  Health plans participating in Medicare also must have an array of internal quality assurance mechanisms. For example, under current program rules, providers serving Medicare HMO members must agree to be reviewed by the plan's quality assurance and utilization management staff and/or committees.

  The Medicare+Choice requirements are similar to those under the current Medicare risk program. HCFA monitors compliance with these requirements through review of health plan documents and by conducting on-site visits.

- Federal Employee Health Benefit Plan. The Office of Personnel Management has yet another set of requirements for plans contracting with the FEHBP. For instance, the program requires participating plans to operate a quality assurance program with specified procedures to address service quality and responsiveness to member inquiries and requests; collect data and develop statistical reports on condition-specific patient outcomes; use a statistically valid sampling technique to measure claims against quality assurance and fraud and abuse prevention standards; and administer and respond to the results of a uniform patient satisfaction survey.

Private Purchasers' Standards

In addition to meeting federal and state requirements, health plans are continually working to improve the quality of health care. Two important initiatives led by the private sector are the reporting of objective, standardized information about plan performance and accreditation.

The best known and most widely used system for reporting health plan performance data is the Health Plan Employer Data and Information Set (HEDIS), which was developed with input from consumer and labor representatives, employers, health plans, and quality experts. One of the HEDIS measures directly relevant to issues raised by S. 249 is the percentage of a plan's female members between the ages of 52 and 69 who had a least one mammogram during the past two years. Other related measures that are currently being tested and evaluated for possible inclusion as future HEDIS measures are: (1) the percentage of women whose breast cancer was detected in earlier stages due to mammography screening; and (2) the percentage of women with abnormal mammograms who received appropriate follow-up care within 60 days.

According to a 1996 study of nearly 400 employers, 54% of companies with over 10,000 employees take into account a health plan's performance on HEDIS measures when deciding whether to offer the plan to their employees. And, as mentioned earlier, Medicare is now collecting HEDIS data on the more than 300 health plans that serve its beneficiaries. Accreditation, by organizations including the National Committee for Quality Assurance

(NCQA), the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) and the American Accreditation HealthCare Commission (formerly, URAC), encompasses a wide array of standards that are tested by site visits from accreditation teams. For instance, NCQA quality standards relevant to several of the issues raised by S. 249 include, but are not limited to, requirements for a quality improvement oversight and implementation committee with active participation by providers; systematic monitoring and evaluation of health care quality and appropriateness; identification of important areas for improvement and establishment of meaningful priorities; use of quality improvement information in credentialing, recontracting and/or annually evaluating providers' performance; verification of providers' history through the National Practitioner Data Bank and other sources; site visits to offices of primary care providers, OB/GYNs and other high-volume specialists during credentialing and recredentialing; and identification of points of access for members for primary care, specialty care, and hospital services.

Accreditation and HEDIS are only two of the many quality-related private sector activities. Every day, private purchasers, taking advantage of the flexibility afforded them, are working with health plans to break new ground. These private- sector-led quality initiatives were never even dreamed of in the old system.

Often, large employers have led the market in a drive for accountability and continuous quality enhancement. Their work with health plans "spills over" to the entire market, as innovations developed for leading-edge purchasers become available to all employers using a given plan. A recent study by the Business Roundtable is revealing about purchasers' expectations. For instance:

- Ameritech monitors its workers' access to physicians and participates in a multi-employer project aimed at holding plans accountable for improvement of the health status of workers with certain chronic conditions.
- American Airlines performs clinical and procedural audits of its point-of-service network and will examine what plans are doing to complement HEDIS measures or be leaders in outcomes measurement.
- Digital Equipment Corporation recently issued the third version of its performance standards, which defines quality of care and services in six areas: access and administration, clinical quality, behavioral health, information management and reporting, health education and prevention, and finances. Digital audits its plans' conformance to performance standards, and it drops plans that do not conform.

Health plans also know that they will be accepted only as long as they provide quality care. As a result, there are literally thousands of plan-devised quality initiatives underway every day. These include, for example, disease management programs, clinical research, payment for quality, consumer surveys, and improved uses of data.

Often, the extent to which health plans listen to and change in response to their members' preferences is not a well understood part of their accountability. For instance, plans learned of consumer frustrations with some specialty referral processes through their consumer satisfaction surveys. In response, a wide array of changes to streamline and improve specialty referral processes have been implemented over the past 18 months. Over time, we will be able to assess which approaches work best and which of the changes themselves need to be modified.

B. Health Care is a Work in Progress

The current regulatory structure has produced accountability while also being sufficiently flexible to allow plans to innovate and respond to the marketplace. Health care is a dynamic "work in progress" which should not be locked into today's conventional wisdom about how care should be organized, since that conventional wisdom is likely to be superseded in short order by a superior approach.

Our medical system has been changing due to a number of factors. Many participants recognized that medical care could be better than it was in the past -- when there was little information about what worked and what did not and when practice patterns varied dramatically from place to place. Patients were offered little information while, at the same, being subjected to much inappropriate, harmful care and receiving far too little preventive care.

For instance, the old system was known for its failure to appropriately screen most women for breast cancer -- leading to the detection of cancer at later stages and unnecessary, premature deaths -- while at the same time subjecting many women to radical mastectomies when clinically-proven breast-conserving alternatives were available. Change was also required so that average people could continue to afford quality medical care, and so that government health care programs would not collapse. Technology also has opened up new possibilities for better medical care.

Due to the changes begun over the past decade, we are headed in the right direction. Policies that would return us to the failed fee-for-service system--such as proposals that would destroy incentives for innovation by micromanaging plan operations--would simply return us to the serious problems that demanded change in the first place.

One of the things we have learned from the past is that a system that provides only unmanaged fee-for-service coverage has significant unintended, but adverse, consequences. For instance, a 1970 editorial in the business magazine *Fortune* summed up the state of American medicine at that time as follows:

> *"Much of U.S. medical care, particularly the everyday business of preventing and treating routine illness is inferior in quality, wastefully dispensed and inequitably financed."*

The old system provided neither oversight nor accountability, and abuses were evident. Consumer advocates were concerned. In testimony before the House Ways and Means Committee in July 1974, Ralph Nader said:

> *"...The health care system's approach to disease is to spend massive sums on treatment and little on early detection or prevention...There is little doubt that a competent health system that serves consumers will not only advance the health of present and future generations but will also implement the economic wisdom that an ounce of prevention is worth a pound of cure."*

Before purchasers and consumers turned to managed care, our system was unmanaged and lacked any tools to produce real accountability for quality or cost. This system's legacy was an economic and quality crisis in American medicine. In the judgement of Surgeon General

William Stewart in 1967, the U.S. health care system of the pre-managed care era was "often of low quality, fragmented and impersonal." And between 1970 and 1980, U.S. spending per person on health care more than tripled.

With the growth of managed care, Americans began to experience the benefits of coordinated care. By integrating the financing and delivery of health care, health plans were able to bring together on the patient's behalf the frequently uncoordinated activities of a whole set of care givers. Wellness and prevention services -- such as mammography screening -- became a priority. And the assumption that more care is always better was questioned. Health plans were able to reduce unnecessary hospitalizations and procedures while improving the quality of care.

In fact, in a 1994 survey of 108 health plans' practice management strategies conducted for the Physician Payment Review Commission (PPRC), Gold and colleagues found that more than 70% of HMOs required health care outcome studies for treatment of particular conditions, had targeted quality improvement initiatives, and used outcome studies to evaluate success and identify areas for improvement. Studies on mammography screening were among the most prevalent. Today, as the health care system continues to evolve, health plans are evolving as well through a process of continuous adjustment and innovation. Breast cancer-specific examples, which do not even begin to convey the breadth of current activity, include:

- Since 1993, Humana Chicago has used multidisciplinary teams to standardize mammography quality assurance and improve practices for evaluation and treatment of breast cancer. The results have been: (1) an increased percent of breast cancer diagnoses made at an early stage; (2) increased rates of mammography screenings; (3) a reduction in the time between a positive mammogram and surgery; and (4) improved quality of mammography imagery.

- Blue Cross of California convened a panel of experts in the field of oncology to develop community-based practice guidelines for breast cancer. These guidelines were developed to provide an educational and advisory tool for providers of care and their patients. The guidelines cover quality parameters, mammography screening, diagnosis, staging, treatment, palliative therapy, follow-up, and standards for breast conservation treatment.

- FHP Health Care has implemented a special streamlined referral program which encourages women to go directly to a radiology center to receive their mammogram.

- Many plans have implemented breast cancer education and outreach programs. For example, Care Choices HMO has developed an ongoing preventive health awareness program for women that includes information on breast self-exams and mammography screenings and a community outreach program on breast cancer prevention. Harvard Pilgrim Health Plan of New England began a peer visitation and education program that provides education and support to women who have been diagnosed with breast cancer. The program addresses topics such as how to live with cancer, the advantages and disadvantages of breast reconstruction, and the side effects of radiation therapy. Prudential HealthCare has conducted a study to test the most effective outreach strategies for improving mammography rates. Phone call reminder and letter mailing alternatives were evaluated. Prudential found that the phone call reminder system was the most effective outreach tool and the results of its widespread use is being tracked across their women members.

Other examples of quality-improving health plan initiatives include:

- Some plans are developing a "mentor" approach and assigned individual staff members to serve as guides to enrollees to help explain plan policies and assist them with any problems.

- Many plans have linked provider payment to the quality of care provided and patient satisfaction.

In addition to improving quality, health plans have tamed the rapid growth in health care costs.

A recent study by the Lewin Group shows that from 1992 to 1996, as health plan enrollment grew, the annual rate of growth in employer health spending per covered worker plummeted from 10.9 percent to 0.5 percent. The lower costs allowed an additional 3 to 5 million Americans in working families to have health coverage who otherwise would have been uninsured.

The challenge for policy makers is to not preempt these purchaser- and consumer-driven innovations and increase inflation in health care by succumbing to pressures to turn back the clock.

II. An Assessment of the Facts

Congress will be best prepared to meet this challenge if it insists on looking at facts before legislating and holds all parties in the debate to the same standard of accuracy. And when Congress evaluates possible responses to reports that something has gone wrong, it should consider the tradeoffs it imposes on all Americans if it fails to take account of the billions of patient encounters every year that provide quality, affordable medical care.

It has become simple for managed care opponents to promote legislation by publicizing misconceptions of health plan practices based on anecdotes. Rarely is data about the quality and affordability of medical care delivered to health plan members considered, or even offered. In the resulting furor--which harms patients by misleading them about their health care system and the health care they can expect, instilling a mistrust of their doctors and treatment advances -- some have chosen to target health plans, thereby inadvertently targeting American families served by health plans. *But time and again, the evidence does not support the restrictions that some seek to promote by anecdote.*

- For example, some have argued that health plans force physicians to abide by rigid and excessively short limits on hospital length of stay. However, a new AAHP analysis of data provided by The MEDSTAT Group found that the length of stay for 95% of health plan members' hospital admissions for procedures identified by the American College of Surgeons (ACS) was within the range recommended by surgeons responding to an ACS survey or longer than the high end of the range. Similarly, 95% of admissions for fee-for-service (FFS) patients also fell within or above the range recommended by surgeons responding to the ACS survey. Likewise, HMO members' exceeded the hospital length of stay recommended in one set of guidelines examined by ACS 62% of the time, compared to 67% for FFS. Both HMO and FFS lengths of stay were below the guidelines in about 8% of admissions.

All of this suggests that physicians exercising their clinical judgment, not health plans wielding rigid length of stay rules, are determining length of stay. Likewise, as discussed below, the evidence does not support claims about health plan practices regarding outpatient mastectomy. These instances of the data failing to support these claims are illustrative -- they are not exhaustive. There are numerous other instances, for example, concerning physician-patient communications, choice of health plan, choice of health care provider, referrals to academic health centers, and physicians' patient load, where the evidence does not support these claims.

A. <u>Health Plans and Breast Cancer: Early Detection and Prevention</u>

Health plans' success at reducing breast cancer mortality is often lost in the debate over length of stay and site of care. Health plans have been at the forefront of encouraging breast cancer prevention and early detection in women -- activities that have made a significant contribution to a reduction in cancer mortality.

Several studies have documented HMOs' success in early detection of breast cancer in women.

- The Health Care Financing Administration (HCFA) showed that 12 different types of cancer, including breast cancer, are diagnosed significantly earlier in Medicare HMOs patients than in Medicare FFS.
- The Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics found that women in HMOs are more likely to obtain mammograms and clinical breast exams than women with old-style FFS coverage.
- The Physician Payment Review Commission (PPRC) found that 62% of women enrolled in Medicare HMOs had mammograms compared to 39% in the FFS sector. PPRC noted that the gap between HMOs and FFS was greatest among low income and African-American women and suggested that network-based plans may significantly improve access to mammograms among vulnerable populations.
- The National Committee for Quality Assurance's Quality Compass reported an even higher overall rate of women in HMOs receiving mammograms in 1995 - 69.1%.
- In 1994, 69% of women in HMOs had a mammography screening -- 9 percentage points higher than the federal Healthy People 2000 goal of 60%.

We have already discussed at length how health plans have been leaders in developing a variety of outreach techniques designed to increase awareness of their cancer prevention and screening services and encourage more women to receive appropriate breast exams. Evidence suggests that this emphasis on prevention has contributed to reduced mortality. In November, 1996, the American Cancer Society announced that death rates from cancer declined for the first time. Breast cancer mortality rates declined 6.3%. This decline was attributed to the "cumulative effects of prevention, early detection, and treatment."

B. Health Plans, Length-of-Stay, and Site of Care

Various bills propose to dictate the appropriate length of stay for medical procedures. Legislators also have expressed their concern about underutilization by targeting specific conditions and procedures. S. 249 is an example of such legislation. S. 249 would require health plans to cover inpatient hospital care following a mastectomy for a period of time determined by the attending physician to be medically appropriate. Health plans would be required to provide this coverage while being barred from using medical necessity and appropriateness criteria applied to other care. S. 249 and other proposals that address length of stay are based on the assumption that health plans use arbitrary length of stay limits that force patients out of hospitals too soon or, in the case of breast cancer, require women to undergo outpatient mastectomies. However, the data does not support the premise.

- AAHP commissioned the MEDSTAT Group, a health care data analysis firm, to analyze outpatient mastectomy rates for privately insured women (average age: 51.6 years) in 1993 and 1994.[1] Rates were analyzed for three types of mastectomy: (1) partial mastectomy with lymphadenectomy; (2) simple mastectomy; and (3) modified radical and radical mastectomy. All three types of health care coverage examined -- FFS, PPOs/Point-of-Service (POS), and HMOs/Other Capitated Plans -- "had fairly consistent rates of mastectomy procedures performed in the outpatient setting." Based on a sample of 2.5 million individuals for each year, the only statistically significant differences were as follows:

    + For simple mastectomies, there was a statistically significant difference in outpatient procedure rates during 1993. FFS coverage had the highest rate of outpatient procedures -- 26%. PPO/POS plans had the lowest rate -- 11%. In HMOs, 17% of simple mastectomies were performed in outpatient settings.

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[1] Data was obtained from the 1993 and 1994 MarketScan® database which represents the inpatient and outpatient health care service use for over 7 million privately insured individuals nationwide.

- In 1994, the rate of modified radical and radical mastectomies performed on an outpatient basis differed somewhat by type of plan. PPO/POS had the highest outpatient percentage (12%) and HMOs had the lowest outpatient percentage (5%). FFS coverage was in between (9%). However, when 1993 and 1994 data were combined, there was not a statistically significant difference in outpatient rates by type of plan.

The data shows that: (1) length of stay for mastectomies covered by Medicare FFS has declined -- by almost 40% from 1990 to 1995; and (2) that women with FFS coverage undergo a large proportion of outpatient mastectomies.

- The New York State Department of Health reports that the majority of outpatient mastectomies done in 1995 were performed on Medicare FFS beneficiaries. Of the 124 outpatient mastectomies performed in New York State in 1995 -- which represented 1.76% of the total number of mastectomies -- 72 were performed on women in Medicare FFS and two in Medicare HMOs. Fifteen were performed on women in private HMOs.
- At the national level, HCIA Inc, a Baltimore research company specializing in health care, analyzed 110,000 mastectomies covered by Medicare, the large majority of which were covered by the FFS portion of Medicare, and found that 7.6% were performed on an outpatient basis. This analysis was performed for the *Wall Street Journal.*

These observations further suggest that whether or not a woman has an outpatient mastectomy is determined by her physician -- not by the type of insurance she has.

III. The Impact of S. 249 on Quality Breast Cancer Care

We believe that the Women's Health and Cancer Rights Act of 1997 does not represent the appropriate role of government in health care. Not only is the evidence to support such legislation lacking, but Congress must also consider the unintended consequences of enacting such legislation.

A. The Danger of Creating Unfounded Concerns Regarding Site of Care

The incidence of outpatient mastectomies in both network-based and FFS plans reflects growing recognition among physicians and patients that outpatient mastectomies can be appropriate in certain cases.

- The Johns Hopkins Breast Center in Baltimore, which has gradually eliminated inpatient stays for some women undergoing certain types of mastectomies, has found that outpatient mastectomies are associated with lower infection rates and high levels of satisfaction among women. (*Wall Street Journal*, November 6, 1996)
- A 1996 study of 525 women who underwent outpatient mastectomies at Henry Ford Hospital in Michigan reported accelerated physical recovery, earlier return to occupational activities, and numerous psychological advantages, such as control, independence, and strong family interactions. (*The American Surgeon*, Feb. 1996; vol 62)
- A 1995 study of 133 women who underwent outpatient partial mastectomies with lymph node removal and 45 women who had the surgery on an inpatient basis at the New Jersey College of Medicine showed that the outpatient group had a lower rate of post-operative infection and reported a high level of satisfaction. (*International Surgery*, 1995; vol 80)
- A 1994 study of 118 women who underwent outpatient mastectomies at St. Peter's Medical Center in New Jersey reported accelerated healing and recovery at home and a high level of satisfaction. (*The American Surgeon*, Dec. 1994; vol 60)
- A 1993 study of 221 women who underwent outpatient mastectomies and partial mastectomies with lymph node removal at the Comprehensive Breast Care Center in Florida found that the women experienced no serious complications, no readmissions, and high patient satisfaction. (*Archives of Surgery*, Oct. 1993; vol 128)

Creating unfounded concerns about outpatient mastectomy could potentially harm women by discouraging them from considering an alternative that can reduce infections, accelerate recovery, and offer familial support. Moreover, as outpatient mastectomies and other procedures are incorrectly held out as inappropriate -- or discussed without all of the relevant information provided as context -- patients will lose their willingness to consider treatment options that may be their best choice.

Over time, the entire health care system will be affected by the stigma attached to innovative, clinically-sound advances in medical care. By promoting the use of practice guidelines and arming physicians with the best available scientific information, health plans currently work with physicians to encourage women to receive the most appropriate surgery -- resulting in more women receiving breast-sparing lumpectomies in cases where total mastectomies are not medically indicated. S. 249 would discourage the acceptance and use of innovative treatment decisions tailored to each patient's individual needs and preferences. Over time, as the use of innovative practices is discouraged, our health care system will innovate less -- to the detriment of all patients. Simultaneously, our nation's effort to promote better quality of care through increased reliance on evidence-based medicine and accountability will be reversed.

B. Prohibiting Health Plan Involvement in Medical Necessity Coverage Determinations

By requiring health plans to cover any length of inpatient hospital care following a mastectomy the attending physician believes to be medically appropriate, S. 249 and similar bills would undermine health plans' ability to promote appropriate and affordable care. This requirement ignores the role health plans play, as part of making coverage determinations, in improving the quality of care.

The large volume of inappropriate care--much of which is harmful--that Americans have received is well documented. In the mid-1970s, when fee-for-service insurance dominated the market, the House Government Operations Subcommittee estimated that there were some 2.4 million unnecessary operations performed every year--many of them unnecessary hysterectomies and cesarean-section deliveries. And the wide geographic variation in the utilization of various health services, including different types of mastectomies, suggests that a significant level of inappropriate and unnecessary care continues to be provided. According to the Dartmouth Atlas of Health Care, despite solid evidence that women who undergo partial mastectomies followed by chemotherapy or radiation and women who undergo total mastectomies have similar survival rates, regional preferences still prevail in determining treatment. For example, 33 times as many partial mastectomies are performed in one part of the country (Elyna, Ohio) as they are in another part (Rapid City, South Dakota).

Over the past 20 years, health plans have been successful in addressing these fundamental quality-of-care issues by working with physicians to reduce inappropriate care and by plan involvement in reviewing medical necessity decisions for the purpose of making coverage determinations. If health plans are forced to cover certain care, even in the face of substantial evidence that the treatment is inappropriate for that patient or may cause harm, plans will lose much of their ability to work with physicians to reduce over- and underutilization.

C. Mandated Benefits

S. 249 includes a provision mandating that health plans that cover mastectomy procedures also cover reconstructive surgery on both the affected and unaffected breast. This government mandate is unnecessary, given the role of market forces and the ongoing voluntary adoption of this health benefit. Virtually all plans cover reconstruction of the affected breast. In response to consumers' and purchasers' needs and preferences, many plans also voluntarily cover reconstructive surgery on the unaffected breast following a mastectomy. Medicare only began covering reconstructive surgery on the unaffected breast effective January 1, 1997. The tendency of private insurers to adopt Medicare's coverage decisions further reduces the need for a government mandate.

D. Micromanagement of Referrals for Secondary Consultations

S. 249's rules for secondary consultations introduce a new level of government micromanagement into plan design. Under S. 249, plans would be required to cover secondary consultations provided by out-of-network physicians whenever the attending physician determined that consultation services were not sufficiently available from in-network specialists.

Health plans historically have encouraged patients to obtain second opinions, and in many cases, require two readings of diagnostics tests before the results can be reported to the patient. In addition, network adequacy standards ensure that health plans have a sufficient number of physicians in their networks who are qualified to provide second opinions. These standards require that networks include an appropriate number and mix of physicians, hospitals, and other providers. In addition, many plans provide for out-of-network care in certain circumstances. These plan practices, in addition to network adequacy requirements, make it unnecessary to mandate in statute access to out-of-network secondary consultations.

Broad authority allowing secondary consultations from non-participating physicians not subject to the plan's quality standards threatens to compromise the quality of care health plan members receive. Plans select physicians who have proven to provide quality care to become part of their provider networks, and hold these physicians accountable for quality care by encouraging use of carefully developed quality standards and by monitoring of individual physician performance. Physicians that are not part of a plan's network are not subject to the plan's standards and are not accountable to the plan for the care that they provide. Plans cannot be assured that the care that members receive from out-of-network physicians is of the same quality as the care provided by network physicians, and therefore should not be forced to reimburse out-of-network care.

IV. CONCLUSION

In conclusion, S. 249 fails to take into account the current regulatory environment, the historical context for today's health care system, and the facts about how health plans and plan providers care for women with breast cancer. The health care system has evolved from a fragmented and costly system into one that is increasingly integrated and accountable. This progress should not be interrupted.

In considering legislation such as S. 249, hard questions must be asked and answered:

- What is the appropriate balance between competition and regulation?
- Has the balance been struck to allow sufficient flexibility to innovate?

- **How should the various layers of regulation relate to one another?**
- **What is the balance among added regulation, affordability of care for businesses, individuals and government, and the goal of insuring more Americans?**
- **Will this added regulation improve the health status of Americans?**

In the recent debate on health care reform, Congress expressed its preference for a health care system based upon competition and innovation, rather than one reliant on federal regulation. This legislation presents a similar choice for Congress. It can either micromanage at the expense of quality and innovation or it can foster a system that promotes informed consumers and allows plans to adapt swiftly to consumers' needs and preferences and promote the delivery of quality health care.

Once again, AAHP remains committed to ensuring that consumers have access to high quality and affordable health care. Health plans recognize the need to improve consumer confidence in the care they receive and welcome continued exploration of how best to achieve this. At AAHP we are undertaking our own exploration of this issue by holding a series of meetings examining the current regulatory structure in health care and in other industries.

However, while we encourage Congress to explore these issues, we also urge the Committee not to act on legislation that will compromise health plans' ability to promote quality care and reduce employers' and employees' ability to afford quality health coverage.

Neil Kahanovitz, MD
President and Founder

CENTER FOR
PATIENT ADVOCACY

Statement

of

The Center for Patient Advocacy

United States Senate

Committee on Finance
Subcommittee on Health Care
Hearing on the "Women's Health and Cancer Rights Act"

Wednesday, November 5, 1997

The Center for Patient Advocacy is pleased to submit written testimony to the Senate Finance Committee Subcommittee on Health Care as it examines S. 249, the "Women's Health and Cancer Rights Act." We commend the Subcommittee for conducting these hearings and for its commitment to ensuring that breast cancer patients have access to the quality health care they need and deserve.

Founded in 1995, the Center for Patient Advocacy is a private, non-profit, grassroots organization representing the interests of patients nationwide. With a growing coalition of over 50,000 "citizen lobbyists," we are dedicated to ensuring that American patients have timely access to the highest quality medical care in the world. Since our founding, we at the Center have focused our efforts on educating the public about managed care and those policies that pose a threat to quality patient care. Hasty discharges after mastectomies, lumpectomies and lymph node dissections and denials of coverage for reconstructive procedures are exactly that – a threat to the health of millions of American women afflicted with breast cancer.

Today, at least 2 1/2 million American women are living with breast cancer. More than 180,000 were diagnosed with the disease in 1996 alone. Unfortunately, for

"Working for Quality Healthcare in America"

many of these women, managed care policies often prevent them from accessing the quality health care they need.

Imagine if you are denied the best treatment possible only because your HMO is more worried about its corporate bottom-line than your health care. You think this sounds unbelievable, it's not. And it happens everyday all across America.

At the Center, we hear first-hand from patients across the country everyday. They call our toll-free 800 line, submit concerns on our world wide web page and send us e-mail messages. In the past year alone, we literally have received hundreds of thousands of calls and letters from patients -- patients who no longer have control over their health care and who are calling on Congress to protect their right to quality health care.

The stark reality is that the decisions affecting a patient's health care increasingly are being made by health plans, not by patients and their doctors. Unfortunately, patients are forced to spend their time, resources, and energy fighting the arbitrary policies of their health plans instead of focusing all their efforts on fighting breast cancer. They must fight their health plans for longer hospital stays. They must fight to obtain coverage for reconstructive procedures. And they must fight their health plans to obtain second opinions.

Far too often, do we listen to the managed care industry dismiss patients' experiences as "anecdotes." To the industry, the people who have been harmed by early discharges are simply stories that don't count. They are isolated incidents that can be ignored and put on a shelf in some dark office. But what the industry must understand is that these so-called "anecdotes" are human beings. They are more than just statistics on a piece of paper or a source from which profit can be made or lost.

The decisions managed care plans make affect much, much more than the corporate bottom-line. They have a profound impact on us all and, in the case of breast cancer, they often mean the difference between life and death.

Is this Congress willing to let the health and lives of the millions of patients with breast cancer depend on the "market?" Do we truly want our mothers, daughters and sisters to have their fates be decided by market forces and competition? By accountants rather than doctors? Or do we value health care and human life more than television sets and computer software?

The Center for Patient Advocacy does not believe that the managed care industry should make medical decisions. Nor do we believe it appropriate for Congress to do so. But it is Congress' responsibility to provide some common-sense guidelines that will protect our nation's citizens from managed care abuses. And if Congress fails to act, patients will suffer because insurance company executives, often with no formal medical training, will continue to dictate how long patients can stay in the hospital, what type of care they can receive, and when, where, and from whom they can receive it.

Women and their families are speaking out and taking part in the legislative process that can bring positive change to our nation's health care system. They are calling on Congress to empower patients and their physicians with the decisions affecting their health care. And that is exactly why the Women's Health and Cancer Rights Act truly will make a difference in the lives of millions of women.

Women facing breast cancer deserve to have the health care they and their doctors believe to be the most effective. Women facing breast cancer need to be reassured that their health will come before the profits of their health plan.

STATEMENT OF THE HON. ROSA L. DeLAURO
SENATE FINANCE COMMITTEE
SUBCOMMITTEE ON HEALTH CARE
HEARING ON S. 249
WEDNESDAY, NOVEMBER 5, 1997

Although I was not given the opportunity to testify at the Committee's hearing, I am pleased to be able to submit this statement for the official record. I would like to thank the Finance Committee for holding hearings on legislation to ensure that breast cancer patients receive appropriate health care. However, I am concerned that this bill is missing key protections for both doctors and patients.

So-called "drive through mastectomies" are becoming all too frequent in hospitals across the nation. Despite a prevailing medical standard of two to four days in the hospital to recuperate and gain physical and emotional strength after breast cancer surgery, insurance companies regularly refuse to cover a hospital stay and women find themselves forced to leave the hospital before they are ready -- often just hours after surgery.

Doctors find themselves in the unfortunate position of choosing between giving the best care to their patients and risking punishment by HMOs.

A study by the Connecticut Office of Health Care Access showed that the average length of stay for breast cancer patients in my home state of Connecticut is decreasing, and is decreasing faster for mastectomies than for other inpatient discharges. The report found that at a time when the average length of stay for all inpatient discharges fell by 23 percent, the average length of stay for all mastectomy discharges fell by a startling 42.5 percent.

This is unacceptable. It is impossible adequately to describe the trauma felt by a woman who loses her breast in surgery. Many of these women are sent home still groggy from anesthesia, in tremendous pain and with drainage tubes stitched to their skin.

To address this problem, and to ensure that both women and doctors are protected from undue pressure from insurance companies, I introduced the Breast Cancer Patient Protection Act. This bill guarantees that a women undergoing a mastectomy may stay in the hospital at least 48 hours after undergoing this surgery, and guarantees a 24 hour stay after a lymph node removal. The patient and her doctor -- not an insurance company -- can decide together if a shorter stay is appropriate.

I'm proud that 196 Members of Congress -- both Democrats and Republicans -- have cosponsored my bill. It has broad bipartisan support in the House of Representatives. Senator Daschle is working to pass the same bill in the Senate.

I am concerned that S. 249 does not guarantee a 48 hour hospital stay, which is the critical part of my legislation. As

Dr. Kristen Zarfos, the Connecticut surgeon who helped me write my legislation, said, the 48 hour standard protects both doctors and patients.

Without this standard doctors are left open to pressure by HMOs to send a woman home before she is ready. Without this standard, doctors are offered absolutely no protection from an insurance company threatening them with the loss of privileges if their patients are not discharged early.

Legislation similar to the Breast Cancer Patient Protection Act has passed in many states, including my home state of Connecticut. But it is important to note that 61 percent of Americans are covered under the Employment Retirement Income Security Benefits Act (ERISA), and ERISA plans are exempt from state law. We need federal legislation to ensure <u>every woman</u> is protected.

It's unfortunate that the Committee did not invite Dr. Kristen Zarfos, who has been nationally recognized as a leader on this issue, to testify today. It is also unfortunate that the Committee did not invite any breast cancer survivors who have experienced "drive through" mastectomies to share their stories. I believe Dr. Zarfos and a survivor would have been able to provide the committee with informative testimony as to the need for a 48 hour hospital stay after breast cancer surgery. I would like to submit her discussion of the 48 hour requirement and the studies presented at the hearing to be included in the record at the end of my testimony.

Since the Committee chose not to invite these women, I would like to share a few stories. Over 8,000 people have signed the Breast Cancer Care Petition, an on-line petition drive in support of the Breast Cancer Patient Protection Act and the Reconstructive Breast Surgery Benefits Act. Thousands have posted personal stories about their experience with breast cancer. I would like to share just two of those stories.

Linda Yarger of Texas, who was allowed three days in the hospital, wrote, "I can't imagine being required to leave the hospital sooner. On the morning of the day that I did leave the hospital I fainted in the shower. I remember seeing purple snowflakes. I collapsed against the shower wall and slid down it. This was very lucky since the "help button" was on that wall. I regained consciousness a short while later and realized that a nurse was standing over me. She had one of those hospital beds with wheels on it but I persuaded her that I felt good enough to ride in a wheelchair back to my room. Once I got home from the hospital I did really well but my mother-in-law (I like her) was there to help with the kids. I can't imagine women having to go home from the hospital in 23 hours. I think it is especially hard when this happens to a single woman who does not have help readily available."

And a Connecticut resident wrote, "On March 20, 1997, I faced a lumpectomy with the removal of 30 lymph nodes. I was extremely depressed and in a lot of pain, and was forced to leave within hours of my surgery. I had no one at home and was scared to death. I desperately needed round-the-clock attention that nurses could have provided. Instead I was forced to go home and be alone. Even though my mother came to check on me she did not stay the whole time. No one facing this should be alone not even for an hour."

These are the people whose lives will be need this legislation to be passed. These are the people whose stories this Committee should be listening to.

As a survivor of ovarian cancer, I know firsthand the devastation that comes with a cancer diagnosis. It's not every day that you come face to face with your own mortality. Asking for a mere 48 hours in the hospital is not frivolous.

I hope that the Committee will remember the stories of these women, and work with me and with Senator Daschle to pass legislation that will truly help breast cancer patients. Thank you.

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COMMITTEE ON COMMERCE
SUBCOMMITTEES:
TELECOMMUNICATIONS, TRADE, AND
CONSUMER PROTECTION
HEALTH AND ENVIRONMENT

WHIP AT LARGE

CO-CHAIR,
MEDICAL TECHNOLOGY CAUCUS

November 12, 1997

The Honorable Phil Gramm, Chairman
Subcommittee on Health
Senate Finance Committee
219 Dirksen Building
Washington, D.C. 20510

Dear Chairman Gramm,

I'm writing to request that you include my testimony which is enclosed in the record of the Subcommittee's hearing on the Women's Health and Cancer Rights Act of November 5, 1997.

I appreciate the opportunity to submit this statement, and I commend the Subcommittee for holding this important hearing.

Sincerely and gratefully,

Anna Eshoo

Anna G. Eshoo
Member of Congress

AGE:mad

Testimony Submitted to the Senate Finance Committee's Subcommittee on Health Hearing on the Women's Health and Cancer Rights Act, November 5, 1997

Representative Anna G. Eshoo

Mr. Chairman, I'm pleased that the Senate Finance Committee's Subcommittee on Health has decided to hold a hearing on the treatment of breast cancer patients. The focus of the hearing, the Women's Health and Cancer Rights Act, introduced by Chairman D'Amato, addresses several important issues relating to the quality of care that breast cancer patients receive. In particular, I'd like to take this opportunity to discuss one portion of this legislation, which provides coverage for reconstructive breast surgery.

Approximately 85,000 American women undergo a mastectomy each year as part of their treatment for breast cancer. While this is a life-saving procedure, it's also a horribly disfiguring operation. Studies have demonstrated that many women say that fear of losing a breast is a leading reason why they do not participate in early breast cancer detection programs. More than 25,000 mastectomy patients each year elect to undergo a second procedure, known as breast reconstruction.

Reconstructive surgery is clearly an important component to breast cancer detection and recovery, yet insurance companies don't always see it that way. Currently, coverage for breast reconstructive surgery is inconsistent. Some insurers will deny coverage by deeming any stage of breast reconstruction cosmetic, while others will cover the first stage of reconstruction, and then claim that their responsibility is complete.

There's nothing "cosmetic" about reconstruction -- it's critical to the physical and psychological recovery of breast cancer survivors. While cosmetic surgery is performed to reshape normal structures of the body in order to improve the patient's appearance, reconstructive surgery is performed on abnormal structures of the body, including amputation. Reconstructive surgery performed after mastectomy should not be viewed as different from reconstructive surgery following the amputation of any other body part. A recent survey conducted by the American Society of Plastic and Reconstructive Surgeons (ASPRS) found that 84% of respondents had up to ten patients who were denied insurance coverage for reconstruction of an amputated breast.

Despite passage of similar legislation in over twenty states, legislation is still needed at the federal level. Even in states with laws mandating coverage for breast reconstruction, women whose health insurance falls under ERISA are consistently denied coverage for this procedure. For example, even though California has a state law mandating coverage for breast reconstruction, California has the second highest number of coverage denials. In Maryland, which recently enacted a similar law, Blue Cross Blue Shield sent a notice to its subscribers stating that it will comply with the state law, but not for federal employees in the area.

To address the very real need for federal regulation, I've introduced legislation in the House of Representatives, H.R. 164, the Reconstructive Breast Surgery Benefits Act. My legislation requires health insurance companies that provide coverage for mastectomies to also cover reconstructive breast surgery that results from those mastectomies (including surgery to establish symmetry between breasts). To further protect breast cancer patients, the Reconstructive Breast Surgery Benefits Act prohibits insurance companies from denying coverage for reconstruction on the basis that the procedure is cosmetic surgery and forbids companies from denying a woman eligibility or continued eligibility for coverage just to avoid paying for reconstruction.

No woman is required to undergo reconstructive breast surgery under the Act and it does not apply to any companies that do not already offer benefits for mastectomies. Further, the legislation permits insurance firms to impose reasonable deductibles, coinsurance, and other cost-sharing in relation to reconstruction benefits. They can even negotiate the level and type of reimbursement with care providers for reconstructive services.

Mr. Chairman, I applaud the Subcommittee for holding this hearing and I look forward to working with my colleagues in both the House of Representatives and the Senate to pass legislation to ensure that breast cancer patients have the means to make the fullest recovery possible from this devastating illness.

Kristen A. Zarfos, M.D., F.A.C.S.
General, Vascular, Thoracic Surgery

November 3, 1997

[redacted]

Dear [redacted]

In response to your request from October 31, 1997, enclosed you will find a summary of some key points on the issue of outpatient mastectomies.

I am including a copy of the Connecticut Office of Health Care Access (ENCL 1 & 1A) report which demonstrated a 700% increase in outpatient mastectomies. In addition, enclosure #2 is a summary of the issue. It lists several articles from respected journals which reflect the benefit of intense postoperative support for women undergoing breast cancer surgery.

In response to your request for research indicating that hospital stays improve health outcomes, I must tell you that there are none for the following reason:

> The trend to outpatient mastectomies began in 1996 in Connecticut. To have reliable statistics would require several years to accumulate enough women willing to blindly subject themselves to a prospective randomized study. Only a prospective, randomized study with a large number of patients can give you statistically significant information. There has been insufficient time to conduct such a study.

This, however, leads to the analysis of what research opponents will present on Wednesday at the Senate Finance Committee hearings. I have reviewed a great deal of the reports on the advantages of outpatient mastectomies, as well as having spent a day at Johns Hopkins University's outpatient mastectomy program. While I am eager to see exactly what papers will be presented (and would encourage you to give me an opportunity to review these for you before Wednesday) I can give you some conclusions on what studies I have reviewed:

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#1) The majority of the reports have not been prospective, randomized studies which are the only statistically significant and valuable information. Rather, they have been retrospective non-randomized reports.

#2) Many of the reports were from outpatient surgical facilities which have a financial interest in performing outpatient breast cancer surgery, skewing their objectivity, not to mention perhaps not offering in-patient care as an option to the patients.

#3) Since the studies are not randomized, women who have the resources and support system self-select to undergo outpatient mastectomies and lymph node dissections. If a woman was opposed to an outpatient mastectomy, she would choose another facility or surgeon and her experience would not be reflected in the study. Again, the study would be skewed by this self-selection by patients. Therefore, the results cannot be extrapolated to apply to all women.

#4) While I have not yet seen the study from Dr. William Dooley at Johns Hopkins University's Outpatient Breast Cancer Center, there are rumors that a report is in the works. Having spent a day in their center, I have a few conclusions:

a) Johns Hopkins University has an exemplary outpatient program with extensive pre-op nursing education, an arrangement with local hotels but a few blocks away for housing, and 24 hour nursing care a phone call away.

b) JHU has a very strong influence in the tiny state of Maryland, with a strong marketing influence presence which can draw a population of women who, again, self-select themselves to this program.

c) To my knowledge, he is not conducting a randomized, perspective trial, but rather reporting a satisfaction report, including statistics showing no adverse outcomes. Again, one must remember that the patients included are those that have the support system to undergo outpatient mastectomies and who had the opportunity to <u>choose</u> outpatient surgeries (unlike the women elsewhere in the country who are mandated to outpatient surgery by their HMO.)

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d) I admire Dr. Dooley's program, but unfortunately the remainder of women in this country have neither the choice nor the sophisticated support system that his patients do. Thus concluding, that one cannot apply his reports and results to be the standard for the remainder of women across the country.

Instead of looking at research that is not pure in nature, I would suggest that the argument against those opponents is that the true value is in the experience of the women themselves who have undergone breast cancer surgery and been released from the hospital prematurely. They have no financial or political incentive, but rather know better than anyone - not their surgeons, oncologist, nurse, HMO reviewer or report writer - what it is like to face having their breast removed and be sent home within a few hours. These women know best. Their experience is the best parameter to assess the outcome of having outpatient breast cancer surgery. They can best tell the adverse outcomes of pain, malfunctioning drains, facing needy families or going home alone.

The best source is to have one or two patients testify in person. Their stories are compelling beyond question.

Other sources for patient experiences include testimonies from the ongoing Sapient Health Network's Breast Cancer Petition started September 10, 1997 (ENCL3). Here patients have logged on their own experience. Perhaps some of the reports of women in each Senate Finance Committee Member's state would bring the issue home to them. As well, the Wall Street Journal reported the experience of a woman undergoing outpatient lymph node dissection in New York on October 23, 1997. The story is vivid (ENCL4).

I conducted a survey of 250 Connecticut women undergoing breast cancer surgery over the past 10 years. None of these women had outpatient surgery. 100% were outraged and angry at even the thought of being denied hospitalization.

When opponents present research showing no "adverse outcome", one must define that entity. No, women do not die from outpatient mastectomies, and there is no increased rate of infection. But if one listens to the women who have endured it against their choice, they all speak of pain and suffering both physical and emotional. Aren't these adverse outcomes? Or, is death and infections the only outcomes we care about? Are women facing a potentially life threatening disease and facing disfiguring surgery expected to endure pain and suffering as well, even though they have paid for basic health care? Is the dignity and quality of life of being relieved of pain too much to ask for as an outcome? Nothing more needs to be said.

The issue at hand is a consumer issue: Women pay health care premiums for basic health care. The day they face a complex, potentially life-threatening and painful, disfiguring surgery, they expect some basic care for which they've paid. There is nothing more basic than having pain controlled after losing a part of your body.

As consumers, these women are not getting what they pay for - basic health care. They have lost their right to this basic health care arbitrarily without any protection.

The 1.6 million women with breast cancer in this country are now turning to their legislators to protect their consumer rights. Just as our legislators have stepped forth and taken the charge to protect the rights of Americans to healthy food by setting quality and health standards, here too women with breast cancer are asking their legislators to protect their consumer rights to receiving the basic health care that they have paid for. This is not a move to have Congress become medical decision makers, but to do what their job is - i.e. protect the rights of their constituents. Without this protection, each year 185,000 women newly diagnosed with breast cancer will potentially face this loss of rights and denial of hospitalization.

It should be reminded that it was neither the medical profession nor the government that singled out women with breast cancer to lose these consumer rights, but rather the managed health care industry. It is neither the medical profession nor women with breast cancer who want so-called "piece meal" legislation that pertains only to them. But until Congress can initiate and pass broader legislation to protect consumer health rights of all patients which is projected at least 3 years hence, (ENCL5), over 1/2 million women diagnosed with breast cancer will potentially face this denial of basic health care they have paid for.

Kristen A. Zarfos, M.D., F.A.C.S.
General, Vascular, Thoracic Surgery

If legislation to protect the consumer health rights of women with breast cancer is to be considered, it must set a standard, just as the government so wisely has done in food health quality standards. Opponents to setting a minimum number of hours length of stay in legislation say that the hospitalization should be at the discretion of the patient and physician caring for her. Ideally, this would be perfect. But the precedent has been set that this does not work. November 1, 1996, The American Association of Health Plans issued a policy statement that their 1,000 members would thereafter allow the length of hospitalization to be determined by the physician and the patient. Nevertheless, since then countless women continue to report being sent home prematurely, before being ready, and against their wishes after a mastectomy or lymph node dissection for breast cancer. For the patient to be truly protected from pressures of premature discharge, she needs legislation that guarantees her a choice of a basic minimum number of hours hospitalization with the stipulation of any further hospitalization determined by her along with her physician.

Consumer rights in this country have been a strong priority of Congress. Let them not ignore the arena that is most important to each individual - their health and consumer health care rights. Through the decades, our legislators have stood up for the rights of the individual in this country. Let them continue to follow that precedent and do so in the arena of consumer health care rights.

[redacted]

Thank you for doing what you are for women with breast cancer.

Sincerely,

Kristen A. Zarfos, MD

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