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April 29, 1994

Melanne Verveer
Office of the First Lady
The White House
Washington, DC 20500

Dear Melanne,

I thought someone over there might like to have a tape and transcript of Mrs. Clinton's speech to the Alzheimer's Association. We continue to hear rave reviews as people across the country see the video. I watched it myself last night and was struck again about what a masterful speech it was.

How many times can we say thank you?

Sincerely,

Judith Assmus Riggs
Director, Federal Issues

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOC. INC.

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TEXT OF HUMANITARIAN AWARD PRESENTATION TO
AND REMARKS OF
HILLARY RODHAM CLINTON

Alzheimer's Association
Public Policy Forum
Washington, DC
April 11, 1994

prepared by PRO-TYPISTS, INC.
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MR. ROTH: Good morning, everybody. Mrs. Clinton, I'd like to take a moment to introduce the people in this room to you. You already know Mrs. Chapman and her daughter, Angie, who will be testifying tomorrow before the Senate Committee on Aging. They represent many of the families in this room. We are the wives and husbands, the children and grandchildren, and friends of people who suffer from Alzheimer's disease. For each of us here, there are tens of thousands of families across the country facing the challenge of Alzheimer's. Every one of us has a long term care story to tell, a story about how the health care system failed our loved ones, just when they needed it the most. We share a common bond of love and pain that brings us together to fight for health care reform that includes long term care.

Mrs. Clinton, we are your foot soldiers in the battle that you and the President have engaged, a battle for health security for all American families. We are honored to have you with us today.
(Applause.)

MR. ROTH: And now, my fellow advocates, it is my enormous pleasure to introduce to you the recipient of the Alzheimer's Association Humanitarian Award. The Association presents this award from time to time to a person in public life who has provided extraordinary national leadership to improve the lives of persons with Alzheimer's disease and their families. It was not difficult to elect our humanitarian this year.

Some day generations of Americans will look back in amazement at a time when 40 million Americans did not have basic health care, when long term care was not considered a part of the health care system at all, when millions of Americans spent the last years of their lives trapped in the world of Alzheimer's disease and the possibility of a prevention or cure was just a dream in researchers' eyes. They'll look back and they'll say, "What happened? Why did things change?" And the answer for any of us that are still around at the time to tell them will be this: "Things changed because we had a President who made health care reform his priority and called the nation to a common cause, and because he enlisted the best possible person to make it happen, Hillary Rodham Clinton."

(Applause.)

MR. ROTH: Mrs. Clinton has approached her task with wisdom and grace, with compassion and humor, with integrity and tenacity, with a fundamental belief in the possibility of change, and always with the interest of the American family in mind. It is with admiration and appreciation that the Alzheimer's Association presents its Humanitarian Award to Hillary Rodham Clinton.

I'd like to ask Shelley Fabares to join me to present the award to Mrs. Clinton.

(Applause.)

MS. FABARES: Thank you. Thank you very much. Mrs. Clinton, we wanted this award to represent to you what this fight we are waging together is really all about. Somehow another plaque or clock or crystal paperweight just didn't seem appropriate. Our award is a photograph of the memorial display we call The Faces of Alzheimer's, made up of thousands of snapshots of people with Alzheimer's disease sent by families from every part of the country. Think of it, if you will, as a family album because we are a family, joined together by the ravages of this cruel thief of a disease. It gives testimony to the fact that this family is made up of people of all ages, races, colors, religions and both sexes. In short, it is the American family. Our display is standing in the Rotunda of the Cannon House Office Building this week as silent witness to the need for health care reform.

We are here to speak for those people we love because they cannot speak for themselves. It is in their honor and memory that we present to you this Humanitarian Award. Mrs. Clinton.

(Applause.)

MRS. CLINTON: Thank you so much for the invitation to be here today, and thank you, Stuart, for your introduction and for all the work you do, and thanks to Shelley for making this presentation. And it is particularly apt because as I travel around the country working on behalf of health care reform, I collect images, faces of the people whom I meet and the stories that I hear, and so now I will have this map of our country with hundreds of faces, most of whom I will never meet personally, some of whom I will perhaps know about through the work that you do or the stories that you tell, but all of whom will serve to remind and spur me on as we go forward in the next month about what it is that we are really trying to do.

This is a debate, yes, about health care reform, but it is about people, it is about the people whose faces are on that map, and it is about the people whose lives we will touch, and it is about all of us in this room. I was in Syracuse last week, at Syracuse University, with Senator Moynihan to speak about health care, and as I finished all of my events there, which included a rather remarkable display of computer technology and how it will link doctors and hospitals, one with the other, so that people will be able to get services at distances from the major medical centers, and after I had spoken in the chapel there to a very enthusiastic crowd of young people, I went outside, where there were about two or three thousand more who couldn't get into the chapel, and I said a few words to them.

And then, as is my custom, I walked down to shake their hands as I moved toward my car to leave. And many of them were very excited about the event and, you know, were saying all kinds of supportive and very personally rewarding things, and I got to one young woman who grabbed my hand and looked at me and said, "My father has Alzheimer's. Please help my father," and her words stopped all of the young people right around her, and they listened as she told me what has been the story of her father and her family since he was diagnosed with Alzheimer's and how little support and little help they really had.

This is not a new story to you who are members of this association and support its work; it was a new story for many of the other college students who stood around this young girl. And it struck me that she was displaying the kind of courage that you display in your work on behalf of Alzheimer's and also your daily caring for the people you love. But she was also an advocate. She was educating those around her as she spoke with me.

So the work that you do is taking many forms and touching people who many never join the association, whom you may never encounter, but who, on a daily basis, are pushing your agenda and our joint agenda for health care reform forward.

I want to thank all of you and the association for your invaluable, courageous work. I want to thank you for your support for research into effective treatments, prevention, and yes, some day, a cure for Alzheimer's. I want to thank you for the support you give to care givers, for your leadership in helping to develop innovative approaches to long term care, and for the strong and loud voices of the Purple People, leading the fight for comprehensive health care reform.

(Applause.)

MRS. CLINTON: Tomorrow Hazel and Angie Chapman, who are here on the stage with us, will be testifying before the Senate Special Committee on Aging. They will be telling their story and it's a story that will be familiar to many of you but needs to be told over and over and over again. They will be talking about Hazel's husband and Angie's father, Tom, who at age 53 has late stage Alzheimer's disease. Hazel and Angie are the primary care givers. Because of Tom's young age, he does not qualify for any Older Americans Act services in his community. The only help they get is from the local Alzheimer's Association chapter which has a small program, funded by the state of Virginia, that provides

adult daycare two days a week.

But Tom's disease is progressing so rapidly that Hazel fears he will have to go into a nursing home in a year or less unless she is able to get more help for him at home or in the community. She has no idea how she would pay for the nursing home care. The family's sole support is Social Security disability and \$85.00 a month from Tom's government pension. He is ineligible for his full pension until the age of 59. She uses that to cover a portion of the \$122.00 a month health insurance bill, but he doesn't qualify for Medicare. He's been on disability for two years.

Hazel just sold her house because she can't make her mortgage payments. She fears she'll have to move into public housing. If she had some help, she could go back to work.

This is just one story, but it stands for millions of stories, and it's a story that we hope will illustrate to the country that people like Hazel and Angie and Tom have been hard working, tax paying, American citizens. They've made their contributions to our country. They have been afflicted by a disease that we still are only learning about but understand the devastation it can cause. I know that Alzheimer's is the most expensive and least insured illness most Americans will likely face. It is a disease that has already hit 4 million Americans, leaving over 19 million relatives and 67 million friends and the extended families of those 4 million to carry the burden of providing the care that the Alzheimer patient so desperately needs.

It is predicted that on the current trend we see that over 14 million Americans will have Alzheimer's disease by the middle of the century, and the cost, which already exceeds 30 to 40 to \$50,000.00 a year, will be astronomical.

I also know that Alzheimer's is not an aging issue; it is a family issue, because when it strikes one person in a family, it strikes the entire family, and what we have to make all of America aware of is there, but for the grace of God, go any of us, and that there are ways that we can help provide support and treatment while we continue to look for the answers in research that will enable us to prevent or ameliorate, maintain and control the effects of the disease.

This is also an issue that raises as starkly as any what we have done in our health care system that is often so penny wise and pound foolish, that does not recognize the real costs, human and economic, of caring for people with long term care needs. It is so unfair and really nonsensical to draw lines that say, yes, we have a difference between medical care and long term care, and we will help your father who has a heart attack but not your mother who has Alzheimer's.

For the first time, we have a proposal in the President's proposal that understands long term care and medical care are part of a continuum of care that needs to be available for people. Today, as you know, many people are forced into nursing homes when a little bit of help would enable them to stay at home. We need to begin, by giving alternatives that will enable those who have Alzheimer's to live with dignity and not in a nursing home as the only alternative where they can get the care that they need. We need --

(Applause.)

MRS. CLINTON: We need to have, all over the country, the types of programs that I have visited in some states that are operating as pilots and models, living hand to mouth because the money may not be there next year, but while they are providing care now are doing so in cost effective, humane ways to Alzheimer patients.

We also need to recognize that it is not just the Alzheimer patient who needs care; it is the care giver who also needs care. We need to recognize that you, people like Hazel and Angie, need respite care, you need time off. If you are willing to shoulder the responsibility that we, as a nation, should want you to in caring for loved ones, we need to help you shoulder that responsibility, so we need more opportunities for you not only to have the help you need to do it but to have the time off that will recharge your battery so you can go back time and time again.

(Applause.)

MRS. CLINTON: Too many Americans today can only get help by spending their way into poverty, and then only if you put your loved one into an institution, which is usually the most expensive thing to do and the last thing that many want to do. It just doesn't make sense that that is your only option.

On this issue sound family policy is also sound fiscal policy, and to those who say -- and there are many who say this -- that we cannot afford long term care in our country, I say we not only can afford it, we have to afford it. It is the most effective way to care for people and to keep families together. And if we are going to say that we are a pro-family country, let's start acting like it in our official government policies.

(Applause.)

MRS. CLINTON: There is a lot of rhetoric out there about what you should do as family members and how you should take care of your loved ones, but you know, rhetoric without help is not only hollow, it's cruel. And what we have done, not just with respect to long term care, but in so many other areas of health care policy, is to hold out empty promises, to make people feel they are all alone in this effort.

Stuart referred to the fact that there are now nearly 40 million Americans without health insurance. There are 25 million more who are so underinsured that the idea that they actually have health insurance is close to laughable. They have it if you consider a \$5,000.00 deductible or a \$50,000.00 lifetime limit or an elimination of pre-existing conditions to be health insurance. I think it's a cruel hoax. And what we have to do is recognize, once and for all, that everyone in this country, no matter where you live, no matter where you work, no matter who you are, should be entitled to health care and should that health care include long term care? Yes, if it's going to live up to the promise that it proposes.

(Applause.)

MRS. CLINTON: Under the President's proposal there will be more support for the one like Lynn Noyes, who is with us today, runs in Northern Virginia. I picked that because it's an example in this area, so perhaps the press and others can actually go see what we're talking about when we talk about these kinds of alternatives. Lynn I met at a meeting at the White House a few weeks ago when she asked me a question about, would you guess, long term care.

(Laughter.)

And since then I've learned that she runs an adult daycare center that is a model for what we are trying to do. For those of you who do not know about it, it is called the Family Respite Center. It was started with the help of the local Alzheimer's Association chapter and it gives Alzheimer's care givers respite. It gives them a chance to go to work during the day, gives them a chance to take some hours off during the day. They also do a lot of great intergenerational activities with the child daycare center there as well.

But even with wonderful programs like this, we know that Alzheimer's and the fear of it devastates families, so we have to make preventing Alzheimer's a high priority. So that is why I believe research, particularly into diseases like Alzheimer's, must be a top priority of any health care reform effort.

Only a few years ago we thought that solutions to preventing or delaying Alzheimer's were far away, but now recent discoveries indicate that the possibility of dealing with and perhaps preventing or in some way controlling the disease more effectively are within our reach. We can see that our investment into Alzheimer's research is beginning to show results. Recent discoveries show that we may be able to delay the onset of the disease, a breakthrough that could reduce the numbers of families and people with Alzheimer's by half.

But we also know that even that is not enough, respite, research. We have to go further. We need to invest more money into Alzheimer's research as the President's health reform proposal does so that we can continue and enhance the progress we have made and beat this disease once and for all.

(Applause.)

MRS. CLINTON: As you fight in the coming weeks and months for long term care and more money for research, I hope you will also fight for the broader cause of health care reform because it is all part of this continuum, this entire system that we need to be changed. There's been a lot of confusion and some distortion around the President's proposal and I want just briefly to tell you how our reform will work so that you can advocate on its behalf and explain it to your friends and neighbors.

There are several major principles that we want to see in health care reform. First, we want guaranteed private insurance for every American, not government insurance. Contrary to what some of the opponents of health care reform say, we want guaranteed private insurance. And remember, that the opponents of health care reform today are the descendants, by direct lineage, of the people who opposed Social Security when they said it was socialism, the people who opposed Medicare when they said it was government medicine, and every one of you who's eligible for Medicare knows how it works: You pick your doctor, you go where you want, and the bill is paid for you to the extent of Medicare coverage. But it's the same argument that we've had for the last 60 years. So remember, when you hear these code words, they're brought to you by the same people who didn't want you to have Social Security or Medicare either.

(Applause.)

MRS. CLINTON: Guaranteed private insurance has to include comprehensive benefits that do include diagnostic services, mental health benefits, and prescription drugs. These are benefits critical to every American, but particularly to people with Alzheimer's. We also want to guarantee your choice of doctor and health plan, a choice that is not guaranteed for you today.

One of the real slick arguments against health care reform is that somehow the President's approach will take away your choice of doctor or hospital or health plan. What is happening today? Those of you who are on the front lines know that fewer than half of Americans with health insurance today have a choice of doctor or hospital or health plan, because what is happening, in an effort to control costs, is you're being told, "Here's the list of doctors you can use under your insurance policy. Here's the list of hospitals you can go to." Choice is being taken away from you right now. It is the President's proposal that wants to guarantee choice of doctor and health plan to Americans.

(Applause.)

MRS. CLINTON: Thirdly, we want to outlaw insurance abuse, and that means eliminating pre-existing conditions as a bar to health care insurance for Americans.

(Applause.)

MRS. CLINTON: It also means, and this is very important to many Alzheimer patients, it also means eliminating lifetime limits. Why should you, when you finally need health care, read the fine print in your insurance policy and discover you have a lifetime limit on benefits when you need them the most. If you pay for insurance you should be able to get health care when you need it, and we will guarantee that you will have that by eliminating lifetime limits.

(Applause.)

MRS. CLINTON: We also believe we should not permit health insurers to discriminate against older people merely on the basis of their age. All of us should be in this together. We ought to go back to an old fashioned idea which is insurance ought to insure the community. Older, younger, middle aged, sick, well, we all ought to be in a big pool together, and in that great big purchasing pool, we should all pay what will amount to lower rates to insure everybody, instead of the kind of cherry picking that goes on now that eliminates coverage for many people and makes it unaffordable for many others. Fourthly -

(Applause.)

MRS. CLINTON: -- we want to deliver health care benefits at work, which is what most Americans are familiar with and what works for them now. We do not want a government health care system. We want to build on the system we have, a public-private system. We have public hospitals, we have public health, but most of us rely on the private health care system. We want to continue by building on that by making it possible for you to get your health care benefits at your place of work. The difference will be you make the decision of your health plan, not your employer. Small businesses will be given discounts. Low wage workers will be given help. We will be able to afford this because, if you add the people who pay nothing now to the entire population that is insured, that is billions of more dollars coming into the system. How do people who are not fully insured now or insured at all get their health care? They get it at the latest possible moment by going usually to the emergency room where we do thankfully live in a country where they do finally get some health care, often the most expensive health care that is available to them. When they cannot pay their bill, the rest of us have our premiums increase so we can take care of them. Everybody should be responsible, everybody should pay something. Let's have a level playing field so that every single American makes a contribution according to his ability to pay so that every one of us is insured.

(End of cassette side 1.)

MRS. CLINTON: -- and does. But their idea of an insurance plan is you pass reform in the Congress, you set up some government body that then decides what the benefits are. I wouldn't buy an insurance policy like that where you pay your money in the front end and you're told later what it covers. Listen carefully, make sure it is in the legislation. The President's reform does that.

Does the long term care option emphasize home and community based care? We don't need more nursing homes; we need more home and community based care options.

(Applause.)

MRS. CLINTON: Ask if the long term care options will be available to persons of all ages, incomes and levels of disability. We do not want any more means testing or any more categorical programs where you have to, you know, run through hoops in order to qualify. We want this to be available to all Americans regardless of their age, their income, their level of disability. The fact that Tom is 53 years old and in the last stages of Alzheimer's should not bar him from getting help for

himself and his family. Let's start taking care of everybody with a long term care program.

And finally, ask does it provide consumer choice, because that's what the President's plan does. All of these features that your association helped us as we were preparing the legislation are included in the President's proposal. So what I hope is that you will go from this association meeting and devote some of your precious time, which for many of you as care givers is so hard to find, but make those phone calls, write those letters, attend those meetings, call those radio talk show hosts when they start going in about government health care and tell them --

(Laughter.)

-- that's not what your for and that's not what the President's for and explain in your most polite voice --

(Laughter.)

-- what it is we are trying to do for Americans, and maybe even ask a question like, "Are you well insured at that little old radio station you work for?"

(Laughter.)

"And if they decided they didn't like the sound of your voice tomorrow, would you have insurance tomorrow?" Let's get people to start cutting through the rhetoric and all the smoke to think about what we are trying to achieve, because I appreciated what Stuart said so much.

But this is not just about health care reform and even looking back from the future about what we've accomplished in health care. This is about what kind of country we are and whether we really care about each other. We have splintered so badly in the last couple of decades. For some of us our country is in many ways not recognizable to the one that we grew up in, the kind of place where people looked out for each other, and regardless of your income or your race or your ethnicity, you were part of an extended community that was there for you. We've gotten away from that and there's more than enough reasons for us to catalog, but we need to go on from where we are. We need to rebuild the American community. We need to start reaching out to help each other. You do that every single day. You are examples of what we want our country to care about again.

So I thank you for what you do and I hope you will help us by stretching even a little bit further to make it possible for us to have health care reform that really does represent the best of America. Thank you all very much.

(Applause.)

MR. MCCONNELL: Mrs. Clinton's time is limited, but she has graciously agreed to take a couple of questions. So if people would like to ask a question, there are three floor mikes, if you would come up to the mike. Hilda? Make your question short and to the point.

MS. PRIDGEN: Okay. I will try. Mrs. Clinton, I'm Hilda Pridgen from the Minneapolis-St. Paul area and I'm a founding member of this organization so I've been around a long time. My husband, Alfred, suffered from Alzheimer's disease for 15 years and my family went through what the people on the stage there are going through right now. It is wonderful for me to see. This is the first ray of hope for our families, that long term care is part of the current health care discussion. I think it's so important. Our families want to continue to take care of their own, but they need help. We need help with the financial burden and the care giving burden. We're willing to do it, we need help, and it's good to hear this. Thank you so much.

MRS. CLINTON: Thank you so much.
(Applause.)

MR. MCCONNELL: Okay, if you want to ask a question, come up to the microphone.

MS. BLIX: I'm Fay Blix from Orange County, California. I'm an elder law attorney here on behalf of my families who cannot speak for themselves. We are greatly appreciative that the President's plan includes home based and community based care, but I have a problem, and that is that many of my families are beyond that kind of care. They are about to face or are facing the ravages of nursing home care and I'm wondering if you can give me any hope to bring back to my families. And secondly, my colleagues and I tomorrow are going to be meeting with our Orange County congressional delegation. I'm wondering if you can give us any help in how to make your message more palatable across very partisan lines.

MRS. CLINTON: Those are two very important questions. We are trying also in health care reform under the President's plan to increase the asset level so that so many families do not have to deplete their assets before they are eligible for nursing home. We think there should be a much higher limit than there currently is, and we also want to help nursing homes to get more incentives to move into subacute care so that they are not also locked into a typical medical model nursing home that may or may not be appropriate for certain stages of certain diseases, including Alzheimer's, so we've got some incentives for changing that as well.

We also believe, and this may sound a little bit unrelated -- but I've had a number of conversations with nursing home administrators. One of the problems -- to be honest with all of you, you know this -- in nursing homes is the high rate of turnover of staff. You have about a 60 percent turnover. That is very difficult to get sustained care. So there are two things that we think will help. One is to have more nursing home beds associated in the same setting with different levels of care, so that people will be moving from adult daycare to maybe congregate living to nursing home, so that the kind of incentives for home and community based care will actually help nursing home care become better.

And secondly, you know, many nursing homes do not provide benefits for their employees, which is one of the reasons you have such a high turnover. Once everyone is required to have health insurance, we believe, and based on those nursing homes that currently provide health insurance that have a much lower rate of turnover, the quality of the staff and the help will be enhanced so that the day to day care giving in the nursing home will be better. So those are some of the things we're trying to do.

And secondly, you know, Orange County, as you know, is certainly one of the more Republican and partisan areas in the country and the congressional delegation there is quite partisan. I think just tell your stories and don't let them come back at you with the rhetoric. I mean, there are lots of ways that we can agree to disagree about the particulars, but we cannot permit this debate to be carried out with kind of political partisan rhetoric; we have to get beyond that. So I think, you know, if they start in about the government this or the government that, I think you are obviously are well trained and articulate and can help with kind of getting the conversation back on track.

And I really believe that this is an issue that should be beyond partisanship. Alzheimer's doesn't point fingers at Republicans or Democrats. I mean, that's not the way it works and we ought to be as strong as we can in saying that this is an issue that is for Americans and there are ways we can do this that will actually save us money over the long run. So I hope you are successful.

(Applause.)

MR. MCCONNELL: Okay, question right over here.

MR. EDWARDS: My name is W.L. Edwards. I'm with the Southeast Tennessee chapter. Mrs. Clinton, we all appreciate your efforts to include community based care in the President's proposal. I wonder if you could comment to what extent including community and home based care in the final bill will be negotiable.

MRS. CLINTON: Well, we certainly hope that it is in the final bill, but we have to recognize that the Congress needs to hear, loud and clear, from Orange County all the way to Maine and everywhere in between, that this is a real need and it should be met. We are certainly hoping that it can be in pretty much the form that it is in in the President's bill, but unless people really get out and work their members of Congress, I can't promise that. It's one of those issues that has to have a lot of grass roots activity behind it in order that it does not get siphoned off, and that's where I hope all of you will help us.

MR. MCCONNELL: We have time for one more question. I apologize but there is a person you can barely see over the heads, a young person who I think deserves to ask a question.

MR. WOODALL: Hello, Mrs. Clinton. My name is Chase Woodall and I'm from Charlotte, North Carolina and I'm almost ten years old. My grandfather has Alzheimer's disease, and we go up my grandmother's house to see him sometimes on the weekends, and we spend half of our time -- you know, he likes to walk off -- in retrieving him and bringing him back, and he'd like to have long term care, and how could she get long term care without being broke? How does your health care plan help? How can it help my grandmother?

MRS. CLINTON: Well, that's actually the question that we've tried to answer for your grandmother and for your whole family, because right now, as I was describing some of the situation that Hazel, the woman who's sitting here with me, and her daughter face, it is not affordable, and it has always struck me as rather odd that we wouldn't help your grandmother or Hazel take care of their husbands at home by giving them a little bit of help or help support an adult daycare option in the neighborhood or the community, but we would pay thousands of dollars for nursing home care. So what we're going to do for your grandmother is provide some financial help and some options that will be available to her so she can keep your grandfather at home but have some help doing it, and it will be affordable to her.

MR. WOODALL: Thank you.
(Applause.)

MR. MCCONNELL: I lied. There is time for one question. This gentleman's been so patient.

MR. BENNETT: And I thank you for the one more question. I have a folder here. I lost my wife in 1990 to Alzheimer's and I've been working with them since. I'm from the Northwest Louisiana chapter. In the folder I have some pictures, some handwritten letters from some of our constituents and the insight of two of my grandchildren on what Alzheimer's meant to them and they're so beautifully written, and I would like to leave this with you, Hillary.

MRS. CLINTON: Thank you, sir, and could I also suggest -- have you kept copies of that?

MR. BENNETT: I have indeed.

MRS. CLINTON: And (recording interruption) and senators and perhaps leave them a copy as well?

(Applause.)

MR. BENNETT: I am very flattered that you and I had the same thoughts.

(Laughter and applause.)

MR. MCCONNELL: Let's let Mrs. Clinton know how much we appreciate her work and how hard we're going to be working on behalf of health reform. Let's thank Mrs. Clinton.

(Applause.)

MR. MCCONNELL: How about another round of applause for the First Lady?

(Applause.)

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