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THE ALZHEIMER'S ASSOCIATION
NATIONAL PUBLIC POLICY PROGRAM



to Conquer
Alzheimer's Disease
and
to Provide
Family Security

Liz / Tulsa.doc

Alzheimer's Disease and Health Reform

The President's health care plan will help combat Alzheimer's Disease by funding new research into the causes of and treatments for Alzheimer's.

The Act increases funding to research into prevention and treatment for Alzheimer's disease, new drug therapies to treat Alzheimer's, and respite services to give those caring for a family member an occasional and much-deserved break.

The President's approach will substantially increase funding to conduct and support research aimed at preventing diseases that strike older Americans. \$2.9 billion dollars will be dedicated to new prevention research, including research targeting:

- Alzheimer's disease
- osteoporosis
- cancers, including breast cancer
- heart disease and stroke.

The National Institutes of Health will give certain areas of research special priority, including elderly health, substance abuse, and chronic health conditions (for example diabetes, arthritis, and heart disease). These efforts will go a long way to uncovering the root causes of many of the diseases that afflict older Americans, and discovering new treatments and cures.

The Health Security Act invests an additional \$2.85 billion in "health services research" -- evaluating the effectiveness and appropriateness of different procedures, and the quality of different kinds of care.

The new home and community-based long-term care plan will cover adult day care -- an important service for those suffering from Alzheimer's, and respite services, which will allow caregivers time to run errands and get a break from constant caregiving.



DATE: _____

FAX COVER SHEET

TO: Liz Boyer

ORGANIZATION: _____

FAX# () 456-2239# OF PAGES: 4FROM: Judy Riggs PH: (202) 393-7737 FAX: (202) 393-2109

MESSAGE:

Hope you got away!
Will talk to you Sunday, if not before.
If you call the hotel, ask for the
Alzheimer Registration desk.

Laurie Meininger is not going to be
able to come after all (if you
were planning to mention her)

4915

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOC. INC.

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Statement of Stephen McConnell, Chair
Long Term Care Campaign and
Senior Vice President for Public Policy
Alzheimer's Association

On behalf of the 137 cooperating organizations of the Long Term Care Campaign, I want to welcome you to today's press conference. I am Steve McConnell of the Alzheimer's Association and I am joined by representatives of a number of the Campaign's key organizations. Among them, AARP, the Older Women's League and the Consortium of Citizens with Disabilities, who you will hear from in a few minutes.

The Long Term Care Campaign is dedicated to a national health policy that provides peace of mind and security for all families and individuals, especially those who now or will in the future confront the devastating effects of a long term, chronic illness.

The organizations in the Campaign represent more than 60 million Americans, including children and older Americans, people with physical and mental disabilities, women, veterans, organized labor and the religious community. Most importantly, we represent American families, those who are digging deeply into their pockets...and their hearts...to find the human and financial resources to meet the challenge of long term care.

The reason for this morning's press conference is to celebrate a major milestone -- that President Clinton has put long term care squarely into the debate over health care reform -- and to announce the next phase of our campaign for comprehensive long term care.

The President's Plan

We applaud the President for his commitment to health reform, for his inclusion of a significant step toward comprehensive long term care protection for all Americans, and for his emphasis on helping families stay together when a chronic illness strikes. The President's proposal would lighten the burden for caring families, to help them continue providing necessary support, to prevent or delay what most people dread ... going into a nursing home. And, it would help persons with disabilities to live independently, in the community, and to join the workforce.

Let me talk about what I know best, working with families who make up the Alzheimer's Association. Caring for a loved one who has Alzheimer's disease is like running a marathon without ever getting to the finish line. It is an unrelenting, round the clock job that can go on for many years. Families get little if any help. And the stress on caregivers puts them at risk of serious illness themselves. When family caregivers are asked what they need most, the overwhelming answer is respite -- someone to provide

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Shelly Fabares (Fab-RAY), who stars in the sitcom "Coach", will present you with the Humanitarian Award. Her mother (?) has Alzheimer's, and she is very active in the Association.

III PARTICIPANTS

HRC

IV. SEQUENCE OF EVENTS

V. PRESS

Open press.

VI REMARKS

Provided by Jason Solomon.

Schedule:

Agenda

→ Hc meeting
w/ President
4:45

TJ Dinner

- briefing
- scenarios
- remarks - tomorrow
- list - tomorrow

- the: 9:45
- Mgt w/ board members / proceeds listing
 - Stuart Roth Intro

• Shely pres

• remarks

• Q&A for 20 min

• work ropeline
(Stuart mod Q&A)

work ropeline

care for a few hours a week "to give us a break." What the system offers them now is institutional care -- after they have exhausted their physical, emotional and family resources.

Respite, day care, personal assistance, home care ... all are necessary components of health reform and, under the President's proposal, all would be available to 3 million persons with severe physical disabilities, cognitive or mental impairments. Finally, families will not be forced to choose between a nursing home and no help at all.

The Next Phase of the Campaign

The Long Term Care Campaign is launching a major new initiative to ensure long term care is included in health reform. Six years ago, few policymakers had heard of long term care. Today, it is recognized by many to be a key component of comprehensive health reform. We think we can claim some credit for this. ~~Since 1987, our grassroots network has enabled more than 100 members of Congress to experience long term care up close and personal by being a "caregiver for a day." We've held town meetings and public events with candidates during two Presidential campaigns. Our families have testified at hundreds of hearings across the country. We've held rallies and house parties, forums and marches.~~

But, fiscal pressures and the immense complexity of fixing our medical system threaten to sweep aside long term care in the upcoming Congressional debates about health reform.

To counteract this, the Campaign is mobilizing the affiliates of our 137 national organizations, whose combined membership represents 60 million Americans, to educate the public and energize them to write to and call their elected leaders in support of long term care. We are:

- o sponsoring hundreds of "house parties" across the country to bring citizens together to talk about long term care and to write letters to their members of Congress;
- o distributing thousands of organizing kits to local grassroots organizations who are mobilizing support on long term care;
- o producing a new video on long term care and health reform and shipping copies free of charge to groups and local campaigns across the nation. (We'll show you a portion of the video at the end of the press conference and give you a nearly completed version if you want it);
- o holding Congressional briefings and participating in hundreds of town meetings and field hearings held by members of Congress in their states and home districts, and

- o sponsoring 150 caregiver for a day events with members of Congress to bring them face to face with the realities of long term care.

As a final note, I want to say on behalf of my organization, the Alzheimer's Association, that along with finding a cure for Alzheimer's there is no more important issue than long term care. It is hard for the families of 4 million victims of Alzheimer's disease to understand a health care system that discriminates on the basis of diagnosis: if you have a heart attack and need open heart surgery your insurance covers you; if you develop Alzheimer's disease you are on your own. We can do better, and health reform will only be complete if we make a down payment toward a comprehensive long term care system.



Dear

Thank you for hosting a Health Care Reform House Party. Enclosed please find your House Party Kit. It includes:

- ✓ The video tape, video guide and instructions
- ✓ A sign-in sheet
- ✓ A sample introduction to the tape
- ✓ Frequently asked questions about long term care
- ✓ A summary of the President's long term care proposals (20 copies for distribution)
- ✓ A model letter to Congress and writing tips (20 copies for distribution)
- ✓ A list of the Members of Congress for your state

If participants in your house party want to do more about the long term care issue, you can suggest:

- Get five friends to write to Congress.
- Write a letter to the editor of the local paper about long term care.
- Show the film at another meeting/with another group.
- Contact the local Alzheimer's Association and offer to help the public policy chair with meetings with Members of Congress, forums, etc that will be happening between now and the end of the year.
- Send names of people who want to receive updates and ALERTS! about health reform to the D.C.

Thank you for helping to make long term care a reality.

Sincerely,

Paul McCarty
Chair, Public Policy Committee

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COOPER/BREAUX HEALTH REFORM PLAN FAILS LONG TERM CARE TEST

The Cooper/Breaux health reform plan (sometimes called "the managed competition bill" or the "bipartisan bill") may be the worst of all of the options on the table in terms of long term care. It takes a gigantic step backward, abolishing Medicaid and withdrawing all federal funding for long term care.

The Cooper/Breaux plan has generated considerable bipartisan support, particularly in the House of Representatives. But it is not clear that Members who are signing on really understand its implications for persons with Alzheimer's disease and other chronic illnesses or disabilities for whom health care means long term care.

Alzheimer advocates must send a clear message to Congress, and particularly to the sponsors of Cooper/Breaux, that this bill is unacceptable, and that its supporters are undermining the interests of Alzheimer families. (See attached cosponsor list.)

Supporters of the Cooper/Breaux bill may try to argue that they will free up money states are now spending for their share of Medicaid acute care costs, which they can use to replace the federal funds for long term care they will lose.

This is not an adequate response for Alzheimer families.

1. Cooper/Breaux will not give states more money for long term care. Some states may actually lose money. Even if they allocated all of their Medicaid "savings" to long term care, there would not have enough to expand services beyond the current Medicaid population or respond to growing need.
2. States will not be required to maintain even their current level of spending for long term care. At a time when states are having trouble balancing their budgets and face urgent competing demands for available dollars, they will be under strong pressures to use any Medicaid savings for purposes other than long term care.
3. Cooper/Breaux takes long term care out of health care reform and says to Alzheimer families that their needs have lower priority. In fact, the goals of health security, universal coverage (or even universal access to health care), comprehensive benefits, or cost containment cannot be achieved unless long term care is part of the package.
4. Cooper/Breaux does not even fully address acute care needs. As many as 24 million Americans would still be uninsured, the benefit package is undefined, and there is no effective cost control. This will leave huge gaps in the system that someone will have to meet. That burden is likely to remain with the states and could eat up any supposed Medicaid "savings".

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On December 7, organizations representing the elderly and younger persons with disabilities issued a Report Card, testing each of these plans on four critical long term care questions:

- Does it provide significant long term care?
- Is the emphasis on home and community based care?
- Is it available to persons of all ages, incomes, and levels of disability?
- Does it provide consumer choice?

The Clinton plan passed the tests. Only one of the substitutes -- the Wellstone/McDermott bill -- got a passing grade. Kassebaum received an incomplete. And all of the rest of the plans failed.

A side-by-side analysis of the long term care provisions of the Clinton plan and the major proposed alternatives is attached. For more information, contact Judy Riggs in the Washington office of the Alzheimer's Association (202)393-7737.



THE CLINTON HEALTH CARE PLAN

The President's plan dramatically changes the way we think about health care in this country. Instead of drawing harsh lines between medical care and long term care, the President is saying that Americans who have Alzheimer's disease and other chronic illnesses or disabilities also have a right to the care they need.

The Alzheimer's Association commends the President not only for his commitment to long term care but to the framework of his specific proposals, which embody the Association's recommendations for appropriate and cost-effective care.

The President's long term care proposals will give families the help they need to care for their loved ones at home where they want to be, without bankrupting the family or destroying the caregiver's health. His plan also takes useful steps to help with the overwhelming cost of a nursing home when that is the only option for care.

The President is offering help now to the 4 million American families who are dealing with Alzheimer's disease today, through his long term care proposals. By recommending increased funding for Alzheimer research, he is also offering hope to the 14 million Americans who will get Alzheimer's before they die if scientists do not find a way to stop the disease. Alzheimer's disease is the leading cause of dementia and the fourth-leading cause of death among adults. At least half of current residents of nursing homes have Alzheimer's disease or a related dementia.

The Alzheimer's Association is the only national voluntary health agency dedicated solely to support for persons with Alzheimer's disease and their families and to research to find the causes and effective treatments for the disease. The Association works through 220 chapters and thousands of support groups in the 50 states.

9/21/93

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DATE: 11/30

FAX COVER SHEET

TO: Mike Lux

ORGANIZATION: _____

FAX # () 456-6218

OF PAGES: 2

FROM: Stephen McConnell

PH: (202) 393-7737

FAX: (202) 393-2109

MESSAGE:

Here's just one example of the kind
of play the Clinton plan is getting
among our 250 chapters nationwide. This
article was front page on the chapter newsletter
from Phoenix, AZ

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✓ SM Public Policy Council

Greater Phoenix Chapter

Serving Maricopa, Pinal & Gila Counties

Fall 1993



Clinton's Health Plan Applauded

Recognizes right to care of chronically ill

President Clinton's health care plan dramatically changes the way we think about health care in this country by saying, for the first time, that Americans with chronic illness have a right to the care they need.

"Most of this country's four million Alzheimer patients are cared for at home by their families."

Mary C. McDonald, Board President of the Greater Phoenix Chapter Alzheimer's Association said, "Medicare and most private insurance do not cover Alzheimer's disease. So the plan's new \$20 billion program for home and community care for people with serious disabilities, including Alzheimer's disease, helps meet an enormous need. The President is to be applauded."

Nineteen million Americans say they have a relative with Alzheimer's disease, according to a recent Gallup poll commissioned by the Association. "We've always said that for every Alzheimer patient there are three or four family caregivers who suffer emotionally and financially in caring for a loved one," McDonald said. "This plan will help ease their burden."

People with Alzheimer's disease and other

chronic illnesses require long term care, which allows families to care for loved ones at home or in cost-effective community-based facilities, or nursing homes. The plan clarifies that all long term care expenses are tax deductible as medical expenses. In some cases it improves Medicaid coverage for nursing home care.

"...the plan's new \$20 billion program for home and community care for people with serious disabilities, including Alzheimer's Disease, helps meet an enormous need."

"Guaranteeing medical coverage for all families, regardless of employment status or health condition is a critically important element in this plan," McDonald said. "People afflicted with Alzheimer's disease lose their jobs, and often family members are forced to drop out of the workforce to care for them. It's common that Alzheimer's disease robs families of job-related in-

come as well as health insurance."

The plan expands funding at the National Institutes of Health for "prevention research" in priority areas, specifically including Alzheimer research. "The pace of Alzheimer research has accelerated so much in the last 18 months, scientists are optimistic about major breakthroughs in the next decade with continued funding," McDonald said.



10/19		# of pages = 1
To Mike Lux	From Steve McConnell	
Co.	Co. Alzheimer's Association	
Dept.	Phone # 202-393-7737	
Fax # 456-6218	Fax # 202-393-2109	

October 19, 1993

TO: Mike Lux and Charlotte Hayes

FROM: Steve McConnell

RE: WALTER ZELMAN'S SPEECH TO ALZHEIMER'S ASSOCIATION

This note is to say "thanks" to both of you for making it possible to have Walter Zelman speak to the Alzheimer's Association's annual meeting this past week-end in Chicago.

In a word, Walter was spectacular! He was clear, inspiring and very informative. Dozens of our chapter leaders from across the country came up to me after Walter's speech to say how much they appreciated it and how enthusiastic they are now about the President's plan.

Most importantly, on Monday, our Association's national board passed unanimously a resolution in support of the President's plan (in its current outline as we know it), with special enthusiasm for the long term care components of the plan.

To show our support, the Alzheimer's Association chapters will be holding 290 health reform house parties on October 21. And, that's just the beginning!

Again, thanks for coming through.

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President Puts Alzheimer's High on National Health Reform Agenda

-File

In a televised speech to Congress and the nation on September 22, President Clinton brought Alzheimer's disease into the middle of the health care debate. Alzheimer families who have mobilized nationwide to draw attention to their needs found affirmation in the President's call for comprehensive long term care for the elderly and disabled, and expedited funding for Alzheimer research.

The President reiterated his commitment to long term care in response to a question from Alzheimer caregiver and Association representative Jean Parker in a nationally broadcast town meeting in Tampa. And in the opening round of Congressional hearings on health reform, Hillary Rodham Clinton repeatedly noted that long term care is an essential part of the full plan, "because it is right, it preserves families, it preserves dignity, and it saves money."

"The President has changed the nature of the health care debate," Association chairman Stuart Roth noted. "He has clearly heard the message of families dealing with chronic diseases like Alzheimer's, and he is saying that we too have a right to peace of mind and security."

Benefits of the health plan

The President proposes that severely disabled persons, including specifically those with cognitive impairment such as Alzheimer's disease, receive a flexible array of services at home and in the community. The program would pay not only for traditional home health services, but also for companions, respite, home modifications, day care, services in board-and-care homes, or any other service defined in an individual plan of

care. Persons of all ages and income would receive benefits; those with incomes over 150% of poverty would pay a portion of the cost according to a sliding fee scale.

The new program would be phased in beginning in 1996. When fully implemented in the year 2000, more than \$20 billion in home and community services would be available to persons who need them. In addition, states would continue

to provide community-based services for low income persons with less severe disabilities. And Medicaid would continue to cover nursing home care, with a new requirement allowing more people to qualify because of higher income and asset allowances for those who require such care.

More funds promised for research

President Clinton has made an equally strong case for Alzheimer research, pledging to "speed research on effective prevention and treatment for Alzheimer's as well as cancer, AIDS and heart disease."

In addition, health care benefits essential to persons with Alzheimer's disease, including diagnostic services, mental health services, and prescription drugs, would be part of the comprehensive benefit package for which all Americans will be insured.

"The President has pushed the door wide open and invited us into the debate," noted Paul McCarty, Public Policy chair for the Association. "And the debate has just begun."

At hundreds of health care action parties across the country on October 21, the Alzheimer's Association launched a nationwide campaign to mobilize a strong and sustained outpouring of public sentiment to convince Congress that long term care and Alzheimer research must be part of any health care plan it enacts.



Health insurance card for Clinton's health care plan.



On September 22, 1993, President Clinton outlined his national health care proposal to the members of Congress.



STATEMENT OF STEPHEN McCONNELL
SENIOR VICE PRESIDENT FOR PUBLIC POLICY, ALZHEIMER'S ASSOCIATION
CHAIR, LONG TERM CARE CAMPAIGN
December 7, 1993

The organizations holding this press conference represent millions of Americans who are left out of our current health care system. The system discriminates against them because the health care they need is not provided in doctors' offices or hospitals. These are people with chronic diseases and disabilities -- people who need long term care.

We called this press conference to issue a Report Card on the health care plans now before Congress. We are grading each plan on one subject, long term care -- the key to health security for the people we represent.

The President gets a passing grade; he has put long term care squarely on the table. None of the plans offered in its place, except for McDermott-Wellstone, passes; one -- Cooper/Breaux -- takes a huge step backward.

To get a passing grade, a plan had to pass four tests:

- Does it include a significant new long term care benefit?
- Does that benefit emphasize home and community based care?
- Will it be available for all ages, incomes, and types of disabilities?
- Will it provide real consumer choice?

We want to emphasize that this is a Mid Term Report Card. These are all good students, and there is still time for them to bring their grades up before the final report card.

The final grade, of course, will belong to the entire Congress. And no one in this room wants that to be a failing grade. Every organization here is committed to working with every sponsor, every Committee, every Member, to make sure that the health care bill Congress enacts meets the long term care test.

Health care reform will not pass any test:

- It will not provide basic security ...
- It will not provide universal coverage ...
- It will not be comprehensive ...
- And it will not control costs ...

Unless it includes real long term care.

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOC. INC.



Testimony of

Stephen McConnell, Alzheimer's Association
Representing the Long Term Care Campaign

Before the
U.S. House of Representatives
Committee on Ways and Means Committee, Subcommittee on Health
The Honorable Fortney "Pete" Stark, Chairman

November 2, 1993

Mr. Chairman. I am here today as Chair of the Long Term Care Campaign and as senior vice-president for public policy of the Alzheimer's Association.

The Long Term Care Campaign is a coalition of 137 national consumer organizations organized in 1987 to get long term care into our health care system. The Campaign is made up of organizations representing older Americans, persons with disabilities, women, churches, labor, nurses and veterans. (I would like to submit a list of the member organizations for the hearing record.)

The makeup of the Campaign underscores a central truth about long term care that too frequently gets missed in the discussion. This is not an aging issue. It is a family issue. It affects people of every age. One third of all persons who need long term care are children and younger adults. But regardless of the age of the person with the illness or disability, every person in the family -- parent, spouse, sibling, child, grandchild -- is affected.

We have a health care system now that discriminates by disease and disability. If you have a heart attack and need surgery, or if you have cancer and need chemotherapy the system recognizes your health care needs and insures them. But if your child has cerebral palsy, if you suffer a spinal cord injury, if you get Alzheimer's disease, the system ignores you because the type of health care you need -- long term care -- is not provided in hospitals or doctors' offices.

97% of American families are uninsured against the devastating cost of long term care.

We organized the Long Term Care Campaign to change that system. You have been with us from the start, Mr. Chairman, insisting that long term care be part of health care reform, as has Mr. McDermott and the supporters of his legislation. Now President Clinton joins us with a far-reaching proposal for home and community care. None of the other proposals on the table offers families any real long term care protection.

The President's proposal contains a number of features which the Long Term Care Campaign considers absolutely essential:

- First, it begins in exactly the right place, with home and community care. The President's plan will turn the system upside down. Instead of forcing people into nursing homes -- where no one wants to be -- his plan provides services in settings that are more humane, more appropriate, and for the vast majority of people less expensive.
- Second, it is a program for persons with disabilities of all ages and income, with protections for low-income families and cost-sharing for those who can afford to contribute.
- Third, it includes specific eligibility language to assure coverage for persons with cognitive and mental impairments as well as physical disabilities.
- Fourth, it provides consumer choice of services and providers.
- Fifth, it is flexible, so that services can meet individual needs, through personal assistance, day care, respite, home modifications, habilitation and rehabilitation, and services in community residential settings.

Speaking on behalf of the Alzheimer's Association, we enthusiastically endorse the President's long term care recommendations. To understand why, you need to understand what a disease like Alzheimer's does to a family. Taking care of a person with dementia is an unrelenting, round-the-clock job that involves the most intimate aspects of daily life. Mr. Jones dresses and feeds his wife every day because she has forgotten how. Mrs. Adams bathes and diapers her father after her own children leave for school. Fifteen-year old Sam comes home after school to watch grandpa so that he does not wander away from the house and get lost.

Families exhaust themselves -- physically, emotionally, financially -- to care for the people they love. And they get little help doing it, unless they put their loved one in a nursing home. Even then, help comes only after they have spent everything -- current income, retirement savings, college tuition funds -- to pay for care.

The system makes no sense. The President would change it.

Of course the Alzheimer's Association is concerned about the cost and quality of care in nursing homes -- at least half of the residents have dementia. But we believe the President is doing exactly the right thing by focusing attention now on home and community care. That is where most people with dementia live. It is where their families want them to be -- in an environment that is as familiar and homelike as possible. By providing some help, through a program like the President is proposing, we make it possible for families to stay together. And we allow families to continue their central role as caregivers, instead of turning everything over to a paid provider.

We do not ignore the central concern Congress must have about cost. The President is proposing significant new expenditures for long term care. But there is mounting evidence that such expenditures will yield important savings, in nursing home costs and in avoidable hospital expenses.

Let me cite just one recent study -- from northern California. Researchers carefully measured the total cost of care for persons with Alzheimer's. One group lived in nursing homes. The other -- with comparable levels of impairment lived at home. When unpaid care is considered, the total cost of care is about the same for persons in both groups -- about \$47,000. But there is a big difference. For those who live at home, three-fourths of the care is provided by family and friends. The total cost of paid care, including medical expenses, is about \$12,500. For those who live in a nursing home, the cost of paid care is three and a half times higher -- \$42,000.

We hear a lot of talk about public-private partnerships. The President is proposing the ultimate partnership -- a partnership with families.

One final comment. However successful we are in helping families at home, there will still be people for whom nursing home care is necessary and appropriate. The President is proposing a change in current law that will make an enormous difference for families who face that decision. He would require that every state establish a medically needy program for nursing home care -- to allow "spend down". This puts an end to the so-called "Medicaid gap" which leaves thousands of families in a dozen states desperate -- with too much monthly income to qualify for Medicaid but not enough to pay the private rate out of their own pockets.

Mr. Chairman, it is easy for families who are dealing with Alzheimer's disease to support wholeheartedly the President's long term care recommendations. If the President's plan is enacted, they -- like hundreds of other families dealing with chronic illnesses and disabilities -- will have help they cannot get today. Finally, they will be part of the system -- and then we can go about perfecting that system.

All of the organizations in the Long Term Care Campaign, and all of the families and 221 Chapters that make up the Alzheimer's Association are prepared to work with you to make that happen.