



Alzheimer's Talks
September 5, 2012
The Stop Alzheimer's Petition Campaign

George Vradenburg: Welcome to Alzheimer's Talks. Today's call is a conversation about building a movement to stop Alzheimer's. We'll discuss a ground-breaking new petition effort and other ways that you can be more involved, and also, you'll hear a brief update from me on the latest news so that you can be a more effective advocate.

My name is George Vradenburg and I'm a co-founder and chair of USAgainstAlzheimer's and motivated with a number of friends, family and now, a number of individuals around the country to stop this disease because of personal impact of the disease on our family, specifically, my wife Trish's mother.

Thank you very much for joining us today and figuring out with us how to develop a movement around this disease. This is a teleconference series by USAgainstAlzheimer's and today's call is sponsored by the Zickler Family Foundation. The petition effort that we're going to describe today is important because we hear - consistently here in Washington, from our congressmen and women and our senators that while they regard this issue as important, it is not a priority for them because they're not hearing enough from their constituents. And as we here continue to drive the effort to get additional research resources into the pipeline to accelerate drugs through the pipeline and approval by the FDA and to get those drugs reimbursed by private insurance and by Medicare, we need the support of constituents around the country to make clear to Washington that this is a priority, that there are families in pain, that there are families who are financially and emotionally suffering from this disease in large numbers and we need that voice to be clear, to be articulate, and to be loud. So, this petition effort is an effort to begin that movement generation.

We're going to have two speakers today. Ian Kremer is the Executive Director of [Leaders Engaged on Alzheimer's Disease, LEAD](#). LEAD is co-convened by USAgainstAlzheimer's and the Alzheimer's Foundation of America. LEAD is a coalition of now over 40 organizations from the government, business, and civic sectors whose goal is to increase attention to awareness of Alzheimer's Disease, its care, treatment, prevention, research, and eventual cure. LEAD is leading this petition effort, which we are all a part of. And Ian will speak in just a minute. The second speaker is Bill Wasserman. He's a principal at M+R Strategic Services, where he has had a wealth of campaign strategy and public policy

experience including other petition campaigns, for example, with respect to Darfur and food safety and others.

If you have a question for anyone during the call, please press star 3 on your phone. By pressing star 3, you will be placed into the question queue. Please have your question ready to share briefly with a member of our staff and then, they will try to get you live on the air, as soon as possible when we open it up for questions.

And now, Ian Kremer, the Executive Director of LEAD, who will describe this petition campaign. Ian.

Ian Kremer: Thank you, George and thank you to all of you who are on the phone today joining us and helping us to build the movement to stop Alzheimer's. I think to a person, we all understand why this has to be done. What Alzheimer's is doing to individuals, what it's doing to families, communities, the country, and indeed, the entire world. We have a crisis of epidemic proportions on our hands. And while it is true that the federal government of the United States is doing more than it has ever done before in fighting Alzheimer's, it is equally true that what they are doing is not nearly enough. So, as George rightly points out, there is understanding on Capitol Hill and in the White House about why Alzheimer's matters. We've done a great deal across the Alzheimer's serving community to educate elected leaders about the importance of this disease. But, they simply have not made the commitment in a sufficient level to change the trajectory of the disease itself. So, at this time, Alzheimer's and related disorders are on a clear path to bankrupt individuals, families, communities, the nation, and the globe. And the response is inadequate. We're grateful for what the government does, but we are also impatient with the pace of change at the federal government level in terms of investing in changing the future.

So, it comes back down to where it always does, which is citizens. People across this country in every major city, suburban community, rural - everywhere in the country to make their voices loud, clear, decisive, and demand change. The first step, not the last in that process is for people such as yourselves to go into your community and help us build this petition's momentum. Help say with a clear and unified voice across the country that things must change and they must change soon and dramatically. That incremental change is not sufficient, it's not acceptable and it will not be tolerated. The petition is wonderful at part because it unifies all of us in the Alzheimer's serving community. It's not just about research to end the disease, it's not just about quality of care, it's not just about the mechanisms that go on in a clinical setting. It is across the board in every phase of this disease and in every way that it affects this country. We all can raise our voices in unison and say to the federal government that it must work much more closely and more effectively, both within its own borders and in collaborating with the private sector to accelerate transformational change to improve care, to give us a real way to have early detection against this disease, early intervention, ultimately a cure, and a way to prevent people from getting the disease. We don't have those things today but they are within our reach if we make the private and public sector investments that are required.

So, this is about building a movement. It is not about supporting a cause. I think we all know lots of things that we can care about when it's brought to our attention. But, there are a handful of things in this world that we live and breathe every single day. And for millions and millions of Americans, Alzheimer's is one of those issues. We can't escape it and we choose to focus on it every day with every fiber of our being because we're committed to ending Alzheimer's as we know it. And our task through this petition and the way we pursue it as individuals as well as through the organizations we belong to, our task is to make sure that everybody that we come into contact with understands how important Alzheimer's is and that if they raise their voice, they can be a part of a movement that will bring change. So, I know Bill will discuss in his remarks some of the specific ways in which each of you can make a meaningful difference in this effort. But, I just want to leave you with one overarching idea, and that is, none of us can afford to let a day go by where we don't speak with somebody or as many people as possible about this petition effort and encourage people to do as all of you will do, sign the petition and spread the word. You can talk to people in your family, who maybe you've never asked to take action before, you can talk to co-workers, to neighbors, to people in your faith community or civic organizations, the person behind you in the grocery store line, and assume that they have 1 of 2 reasons to care, either Alzheimer's has struck their family or they know it could. Everybody - everybody in this country has a stake in ending Alzheimer's. Give them that opportunity. Use your voice to create change. Use your voice to help end Alzheimer's.

George Vradenburg: Thank you very much. And to Ian's last point, our polling and surveying indicates that 1 in 3 Americans will say that they have Alzheimer's in their family in some fashion. So, that's not only turning to the person behind you in the drug store or the supermarket line, 1 in 3 people. And if you're one of those - 1 in 3 people is going to actually have been affected in their family, and as Ian said, if beyond that, certainly, there is great anticipation and anxiety about getting this disease in their older years.

I'm about to turn it over to Bill. But again, if you have a question for us, please press star 3 on your phone and we'll try to answer as many questions as possible in a few minutes when we open this up for questions and discussion. Bill Wasserman, please introduce us to the content of this petition and how we intend to proceed.

Bill Wasserman: So, I just want to reinforce how important this kind of mobilization effort can be to growing a movement. I think, like many of you on this call or all of you in this call, but just by the fact that you're here, I'm an activist and I've been involved in these kinds of efforts in the past, and I know that it can make a difference. If we can reach hundreds of thousands of people, we will show policy makers that Americans care and demand action. But what we all need to do is tap into our own networks so that we can contribute to building a movement.

And like George said, I've been involved in similar efforts on a range of issues, from public health concerns to human rights. And I just wanted to tell you a little bit of the story of one example that I

think helps reinforce what we can achieve and how quickly we can achieve it. In 2006, a coalition of faith and human rights groups launched what they called A Million Voices for Darfur. And they did that at the time when very, very few people in the world knew where Darfur, Sudan was nor did they know about the genocide and human rights tragedy that was going on. But, they knew that they needed to build a constituency in order to convince then President Bush to lead on the issue and eventually to ask President Obama to make it a priority on early and the first day in office. And while it took about 7 months, this movement that emerged around this issue reached a million people to take action, to sign in both an online or an offline printed petition calling for the deployment of UN peace-keepers and calling for US leadership. And as important as achieving that million-person goal was... and it was important, it helped build a movement and engaged a lot of people, and showed policy makers in Congress and the administration, that people cared about what was going on in a far off place. What it also did was, the process engaged over 3,000 community groups, over 150 national organizations and 30,000 individual activists helped participate in the recruitment and achievement of this bigger goal. And the community, the number of people affected directly or indirectly by Alzheimer's suggests to me that we can achieve at least that level of success, if not more, and that the need is absolutely great, that it really is one of the most important issues of the day.

George Vradenburg: Would you just describe the content of the petition, Bill?

Ian Kremer: I'm not sure Bill heard the question. This is Ian. I'll...

George Vradenburg: Ian. Why don't you take the question of what is the call in the petition?

Ian Kremer: Right. The call in the petition is wonderfully straight-forward. And everybody on the call this morning is able to read the text or petition if you go the USAgainstAlzheimer's website. It's just usagainstalzheimer.org. So, if you go there, you'll be able to find the petition and read the text.

The gist of the petition text is to say that we are calling on the federal government, the Administration and Congress, to move much faster and with much more strength to implement all elements of the first-ever National Alzheimer's Plan that was voted into... It was a law passed unanimously by Congress late in 2010, signed by the President early in 2011 calling on the federal government to write a National Alzheimer's plan. And that plan was actually written and published by the Department of Health and Human Services this past spring. So, the federal government has begun an implementation. But, what we are calling for is much more vigorous implementation and resources to back it up, to create truly transformational change. So, the petition by design does not attack anyone. It's a very positive petition in its nature, reinforcing to all federal officials the urgency of the crisis before the country and the clear steps that the federal government needs to take, steps that are already identified. But, we need to see the resource commitment at an accelerated pace to see the goals of that National Plan realized. The goals are smart, the goals are clear and informed, they just aren't adequately resourced. And that is primarily what we see an opportunity to affect through building this movement.

I should also say that building this movement begins with the petition, but it doesn't end there because those of you throughout the country that participate in this petition drive will also be given the opportunity, should you take it, to engage in community level activism, around a range of Alzheimer's issues. We will not end Alzheimer's through one petition submitted to Congress, but what we will do is show Congress the people that are about to inundate them, as long as it takes, as loudly as it takes to see the end of this disease. So, you will have the opportunity, as petition signer to chime in and alert Congress and the Administration time and time again when there are concrete actions to be taken to advance the struggle against this disease, to improve quality of care, to advance the science, to get rid of the backlogs and the federal drug approval process that slows down treatment when we are able to get those scientific breakthroughs. We have to make sure not only that the right medical advances are made, but that they are adopted by the general public, that docs use them, that patients have access. So, this is a long battle, and that's why it requires a movement. The petition gets us started on that road and you all can be a big part of it.

George Vradenburg: So, George Williams from Nevada sent in a question before this call. How much is funded each year by Congress for research and development, research and treatment of Alzheimer's, and how does the funding compare to funding for other diseases? And I thought I would use that question to sort of key off why this petition is so important. NIH every year devotes about \$6 billion to cancer research and development, about 4 to 5 billion for heart and cardiovascular research efforts, about \$3 billion for HIV and AIDS cures and research, and 450 million for Alzheimer's Disease research. Now, that disproportion, or that particular allocation is the result of politics and history. Nixon kicked off a war on cancer in the early 70s, there was an effort against heart disease in the early 80s, HIV/AIDS research efforts began late 80s and 90s. The consequence of the investments that were made on those diseases are that, today the number of deaths every year from cancer are down, not as down as fast as we'd like but they are down. The number of death each year from cardiovascular disease are down, not as much as we'd like, but they're down. HIV AIDS deaths every year are way down from what they were in the early and mid-1990s. The number of deaths every year from Alzheimer's Disease over the course of the last 8 years is up 60%. So, the consequence of the inadequate investment in Alzheimer's research is death. And we have to be very blunt about this and we have to get angry about the misallocation, or shall we say, the inadequate allocation of resources to Alzheimer's research. We have to get angry, we have to get engaged, we have to be enraged, and we have to say that business-as-usual is no longer acceptable.

It's intolerable that we're sustaining this number of deaths every year from Alzheimer's, a growing number... as we... as the baby boomers age. And inadequate research is being devoted to that effort. Carol Bayard of New Jersey asked why has so little progress are made to end this tragic disease? If you compare the relative investments and this disease research field with those in the heart, the cardiovascular or cancer and HIV field, it's clear that inadequate research money is devoted

by NIH to this research category... are killing people. We are not developing the basic and translational science we need at the speed we need in order to get out of this disease.

Ian Kremer: George. I want to pick up on that point just for a moment and... You know, I think a lot of us that have devoted our lives to fighting this disease, have, at times, felt very helpless against it because we don't have disease-modifying drugs, we don't have a known way to prevent or cure the disease. In many cases, we don't even have effective treatment. And it can be incredibly demoralizing. But, the flip side of that is recognizing the opportunity and how we can affect change and create a better future.

We know from the experience in those other disease states that you mention, and I'll just use cancer, HIV, and heart disease as three of many examples. We know, for a fact, if you make the investment, both public sector or private sector in advancing the research, and you sustain that commitment and you grow that commitment, you win, you save lives - you save millions of lives and you save what this country would otherwise face. We know if we make the investment that deserves to be made in Alzheimer's science, that we will win the fight against Alzheimer's. And the question in my mind is only this, how fast or how slow does this country want to defeat Alzheimer's? We'll get there eventually, it is within our power if we choose as a country to make the smart investment in a sufficient degree now, to get out ahead of this disease before it claims another generation.

George Vradenburg: I would simply make one final point and then we'll move to questions. It's going to take us some time to get a means of prevention or treatment of this disease. In the meantime, families, individuals are suffering. And so, a major significant element of this petition drive and the development of this movement is to devote the resources and the smarts to how to support our families who are living with Alzheimer's today and sustaining the financial, emotional and other impacts of this disease in their family life. There are some really innovative efforts of people around the country to provide much more dementia specific care and support, and we need to multiply the best practices in the area so that every family in the United States that is sustaining the pain and suffering from this disease is supported and supported well. Because the people with Alzheimer's and the family and caregivers that take care of them are deserving of the same respect, the same attention, the same commitment of resource as anyone else suffering from a disease. And so, we must remember because it will take us some time to get to a means of prevention or treatment of the families that are sustaining the pressure, stress and pain of this disease as we go forward.

Now, if you're motivated by what you've heard so far, to help in this effort, please press 1 on your phone and someone on our staff will get back in touch you, to talk with you about ideas that you have or way that you would like to help. And with that, I'd like to open it up to questions. And maybe, let's start with Patty... Is it Abrego? Patty from San Antonio, Texas?

Question: Yes, Sir. It is. I am the unfortunate daughter of my mother, who passed away August 15th, a little more than 2 weeks ago after about 12 years of suffering with this disease. I have a unique

perspective in that I am a registered nurse with 35 years experience and did go through the HIV epidemic that you were speaking about and saw the effectiveness. I was a nurse who actually was helping patients in the clinical trials, with the medications that are now approved today, not only with HIV but with the type of leukemia that my sister had that I just read today, that they just approved another drug to treat this terrible disease that took her at age 47.

My mother was a very active woman with her mind and her body. And of course, the signs and symptoms started with the dreaded decline. My family decided that we were going to take care of Mom at home. It took all of the resources that my mother and my sister had together, I had a sister who did not marry until her 50th birthday, which was my mother's 79th birthday. My mother was 79 1/2 when she passed. It took the Social Security check that my dad left to pay for us to have a 24/7 caregiver. We are a middle class family. My sister took my mother to the doctor religiously. My sister would lift... My sister is overweight and she would lift my mother without a hospital bed into a wheelchair and wheel her around their neighborhood for my mother to get some outside activity. Because my mother had such a great Social Security check, she was not entitled to medicaid. She was not entitled to a provider and heaven knows our 24/7 caregiver, that little woman needed a break too. And listening to, "Hey. Hey. Hey. Hey," for hours at a time, those of you that have spoken... that have family members with this understand... understand exactly. When I heard that talk last month with Sargent Shriver's son... We all understand, as we have a family member with this, we understand.

I listed yesterday three things that I thought were important. And as we were talking, I've actually reversed those things. I had diagnosis, which... You talked about the research and development, which I thought was incredibly... You hit it right on the head, because I saw that with the HIV epidemic. 100%. I was very very involved with that. Number 2, I had treatment. And number 3, I had the caregivers and resources, that they need for years. I've reversed that. Number 1, right now, needs caregiver resources. And it's hand-in-hand with diagnosis and treatment. You almost can't split any of them because these caregivers... We are the baby boomers. My sister is the baby - she's 50. I'm 57. And the toll that this has taken... My sister married for the first time at age 50 because we finally got a caregiver 3 years ago. We were able to afford a caregiver and she met someone and finally started a new life. So, where are these resources going to come from the middle class that doesn't qualify for... I mean, she was buying diapers, she was buying special food, where, you know, we... They wouldn't buy the special cushion for her bed, well, I found it, by God, for \$58 and Medicare would want the same... same bed mattress for \$400. You know, why isn't there economic fiscal accountability for these things? For these things that these family members... They're not charging for their time to take care of them. And the nursing homes are closing.

I'm sorry. I'm rattling on but there are a ton of issues here and it sounds like your petition is doing a very good job at addressing them and I have indeed signed the petition, and I have indeed written

Senator Hutchison and Senator Cornyn from Texas for their responses on this and I'll let you... I'll let you respond. Thank you.

George Vradenburg: Thank you very much, Patty. You pointed out the fact that the urgency is now and the families that are trying to sustain this... the pain. And their families are not only needing support now, but the recognition that most of the care giving that occurs with respect to these victims is occurring by volunteers. Volunteers is a strange word here. They're being... It's being undertaken by family members and friends who are sustaining the effort, and they are relieving the United States government and Medicare and private insurers of the cost of this care. And they're not being paid or compensated or otherwise, economically, mitigating their cost. You put your finger, I think, on an extraordinarily important point. I thank you for signing the petition. I also want you to press 1 on your phone so that we can get back in touch with you and rely both on your passion and your sense of urgency, and almost anger at the current state of affairs to help us in your professional circles and with your advice and counsel on how we can make progress against this disease. So, I deeply appreciate your comment, Patty.

Ian Kremer: I also want to thank you for your support of your family and the example that you set for so many others. And your willingness to share your story. I think that's what we need everyone on today's call to be willing to do.

George Vradenburg: And you need to tell it, and retell it and retell it so that people begin to understand why it is the current state of affairs is intolerable.

Alan Arnette, who is on the phone and who has a question or a comment and Alan, himself, is a very visible extraordinary advocate who has climbed the mountains to raise the awareness of Alzheimer's Disease and the funds needed to fight for it. But, Alan, we are honored to have you on the call and look forward to your comment and question.

Question: Yeah. Hi. Thanks, George. My question is... Obviously, what you're doing is fantastic, I fully support it. I also signed the petition. My question is that, you know, we've seen these petitions before, mainly through the Alzheimer's Association. They had a very public effort over the last 12 to 18 months, which was on behalf of NAPA and others. So, my specific question is, how is this different and why do we think the results will be different this time with this approach. Thank you so much.

George Vradenburg: Well, let me comment and Ian may have a comment as well. We have actually talked to the Association and suggested that their efforts be joined with these so that we can aggregate the effort that we are putting into this petition drive so that... In fact, we intend to work with this... This is one movement. It's not organization-based. This is a movement-based based upon what people are experiencing out there and around the country. So, we have invited them to aggregate the numbers that they generate in their petition efforts, which are parallel to this, with those that we generate through our coalitions and our efforts around the country in community-

based organizations. The simple fact of the matter is, that as good as the Association is, and I have deep respect for their efforts, they don't touch everybody that is affected by this disease. And they don't affect... they don't touch all the community organizations and all of the community-based organizations that are serving our Alzheimer's population. So if we can join with them, if they will join with this and we aggregate those efforts, we're hopeful that we can generate a genuine nationwide grassroots constituency-based movement. Now, why is that? Will the results be different? I think this is a cumulative process, quite frankly. I do think the Association took the lead, we were supportive but the association took lead, in the passage of NAPA. We are jointly now working together, with the Association on all the implementation steps with NAPA. But again, as we found out from any number of other industries ... I come out of business so I think in industry parlance ... One company cannot... cannot do it all. In innovation, the urgency that's created by multiple people with multiple ideas and multiple approaches will tend to generate more innovation, more energy, and more passion, and more commitment. They want a world without Alzheimer's, we want a world without Alzheimer's by 2020. Those are quite consistent, we work hand and glove with the Association. And yet, we want to generate a nationwide grassroots movement around this disease through the Association and through these efforts, which will be perceived by political Washington as a unified effort to overcome the lethargy, the business-as-usual kind of attitude on the part of Washington in respect to this disease. To do that, we need all hands on board defeating this disease, changing the politics of business-as-usual around this disease, it's going to be a team sport. And we're going to be a part of that team and so will the Association.

Ian Kremer: And I agree with every bit of that. I spent 15 years working at the Alzheimer's Association and, like George, have enormous admiration and appreciation for everything the association does. The only reason I left the Association was for this opportunity at LEAD, which is by definition a coalition of organizations. And it's because I have enormous faith, and I think backed up by a lot of practical experience of watching coalitions change the trajectory of challenges confronting this country.

LEAD is a coalition, as George said, of more than 40 organizations, I think we're actually getting closer to 50 as the coalition grows. But, it's a coalition that in this petition effort, welcomes all organizations, whether those are corporate entities, whether they are faith committees, whether they are civic associations, whether they are non-profits, every organization in this country is welcome and encouraged to be part of this petition effort. Large or small, north or south, east or west, focused exclusively on Alzheimer's and the related disorders or on any other issue where they recognize that Alzheimer's profoundly affects the people that they serve. So, if the Catholic Church wants to be a part of this petition initiative, we welcome them with open arms. If the Kiwanis Club, or the Fraternal Order of Police, or the local hospital, or the local girl scout troop wants to be part of this petition because they realize that Alzheimer's already has a profound impact on the future of this country, and that impact will either grow, if we ignore it, or we have the power to measure that

impact and reduce it, we can do that together. Everyone is welcome. And every individual in this country as well.

Early in the call, I described how you could go on, usagainstalzhaimers.org and find the petition if you want to sign it. We will make sure that everyone participating in today's call also receives information about how you can download a copy of the petition, print it out with signature blanks below the language of the petition and share that in your community. And I would encourage everyone to keep your photocopier on. Make as many copies as you can make use of, and take this petition with you everywhere you go. Take it to work. Take it to your community of faith, take it when you're going to the movies or going shopping. Always have it with you in your pocket, in your purse so that when you begin a conversation with someone about how they have an opportunity to make this country succeed in ending Alzheimer's, you have an opportunity to take that petition out, put a pen in the hand of the person you're speaking with and have them join this movement.

George Vradenburg: Just as a reminder, if you have a question for anyone during the call, please press star 3 on your phone. By pressing star 3, you will be placed in the question queue. Please have your question ready to share with member of the staff and we'll try to get you on the air, as soon as we can as we have opened up this request.

Michael Ellenbogen, a strong early onset advocate for increased activity in the space. Michael. We are enormous fans of what you do and your passion and your energy and your creativity. So, I'd love to hear your comment and/or question with respect to this petition effort.

Question: Thank you, George. Basically today, I have a comment and I guess, my perspective on some issues relate to Alzheimer's. Just today, I had an opportunity to speak with a large government official in HHS. And the one thing that came back out of his mouth was, he would love to see more people focused on Alzheimer's, like they do for cancer and other things. And I told him, I hear him so loud and clear and I'm so frustrated, just like he is because, I've been advocating now for a couple of years. And it seems that every time I go into these forums and I talk to people who are caregivers or have been touched by Alzheimer's, or even the people who have been touched by this disease directly... All I keep hearing is, "Oh, I don't have time for doing this," or, "My loved one is too busy. I have to take care of them. I don't have time to advocate," and... Or, "I hear it's been... It's too late for them, they don't have... You know, there's no chance for their survival anymore. So, it's like, once they're gone, I'm no longer going to advocate, I just want to forget about this disease.". But, I think what people are missing the whole point is. Well, there... "It's too late for people like myself and the loved ones who are being directly impacted by this disease now.". But they need to think about is their daughters, their sons, their relatives who may get it 5 years down the line, that's how they need to think, because if we can do something now and start that movement and make it expand, just like you say, we can then get people together and hopefully have a cure for the time when they... you know, their loved one might get it later on. So, I think it's important for people to change their focus and not

think of what it is like today for their loved ones but what you might may be able to do for your loved one if they get it in the future.

George Vradenburg: Well, you're absolutely right, Michael. And it is... Let's face it. The families are stressed and they're tired and they frustrated and to some extent, they're without hope. And we have to turn that around. And it's going to take us some time. But, the urgency of starting that process is now. And taking action to begin to try and change that attitude is now. And it will take some time. But, the power of a movement is at the edge, it's not at the center. And so, we need to light a fire at the edge, that is the edge of this network are people like yourself and other families that are suffering. Because if it's 1 in 3 families that have felt the pain of this disease. There are an enormous number of people out there and we need to find leaders like yourself, who are stimulating and catalyzing this movement, and we need to multiply the Michael Ellenbogens by a hundred, then by a thousand, then by ten-thousand. But, we're not going to get millions and millions until we get 5,000 people. So, how do we find the Michael Ellenbogens? So, this call is sort of the kick off of an effort to find a thousand Michael Ellenbogens. And then, 10,000 Michael Ellenbogens. So, we need to identify those hard charging, very smart, very articulate people like yourself who will take this on and figure out how to make this movement go. So, you're one of them, Michael. So, push the 1 on your phone because you're one of them and we will be working with you. And as we begin to collect a variety of networks over the coming months, we'll begin to identify more and more Michael Ellenbogens.

We are beginning to organize a WomenAgainstAlzheimer's effort, we're beginning to organize an African-American network because those communities are touched... they're touched in spades. And as we begin to find, now, we're up to 10 states, 12 states with the women's effort, with about 10 states with the African-American network in terms of leadership and as they get launched this fall, we'll have an army of leaders from communities around the country who will begin to identify those like you who are so articulate and who are so passionate and so committed, they will begin to put together that structure. It's going to take elbow grease. But, damn it, if we don't do it, who's going to do it? I'm sorry. With deep respect for the Association, it hasn't lit the fire yet. But between us and the Association, we should light this fire, and we should get angry, just like you're angry, we need more of you. You're not alone, Michael. Definitely not alone and you now have the support of this coalition and hopefully, the thousands of Michael Ellenbogens that we can begin to develop over the coming months. And then the ten-thousand. And then, we'll have a movement. But you're going to be one of the leaders and you can help us draw a change in attitude and a change in perspective, a change of passion around this movement. And we look forward to working with you.

Question: I would support you guys any way I can.

Ian: Thank you, Michael and everybody. I want to go back to something that Bill Wasserman shared early in this conversation. That was about his work in the Save Darfur campaign. There are very, very

few people in this country with a direct connection to what is going on in Darfur. But, we all understand why that matters. And Bill and those that he worked with were able to organize over a million Americans to speak loudly, clearly, and powerfully about the need for change and about how this country bore a responsibility for creating that change. If a million people in this country can stand up and demand action from the federal government and succeed in achieving action and meaningful transformative change by our federal government around Darfur, which is vitally important, we all understand the importance of human rights around the world. But, if we can get a million Americans to stand up about something going on a continent away, surely, surely, we can get millions and millions of Americans to stand up about what's going on right here at home in terms of Alzheimer's Disease. These do not compete, but the point is just like the point that George was making about, Cancer research, AIDS research, heart disease research, we have success that we can emulate.

We know that there is a model out there to create change, to communicate to our government the urgency of them taking a fundamentally different path in fighting against a critically important issue. It was done on Darfur, it can be done in Alzheimer's. The powers is ours, as George says, each one of us as an individual has it within ourselves to make a choice about whether we will choose to engage everyone we encounter in the opportunity to demand change from the federal government. So, at this point, I'd like to ask, if anyone on the call would like to offer their own ideas about how they can share the petition in their community and encourage people to join the movement. Bill. Do you want to add anything or would anyone else who just called in today like to add any ideas at this point?

Bill Wasserman: Yeah. First of all. I'm sorry for getting dropped from the call. But, I think Ian, you picked up on what really was my most important point, which is on an issue that seems very distant, there'd been successes like this in the past. And that they are successful in getting the attention of policy makers. But, it takes the cumulative action of many many people. And I think what we'll really... we'll know we've succeeded when we have many many more leaders like those on this call, engaged together and pushing up against both the policy objectives, the public education objectives of... and engagement goals of this effort. And few organizations or campaign efforts like this movement building that we'd start with such a... such a healthy-based of organizational commitment that we... We need this common goal and we need... And we need to get going with the actions. So, I agree with Ian and let's... I think we'll benefit from the creativity of the people on the call and see if people have ideas that we can... they can share and that we can help implement.

Ian Kremer: And I... I want to turn in just a moment to Edith Royal. Who's calling from Austin, Texas. But before we go do Edith, I wanted to just make a quick observation. Already, half of you on this call today have pushed 1 on your phone to indicate to us that you want to have a conversation after this call to explore ways that you can make a difference in accelerating the end of Alzheimer's and helping to advance the petition effort as it builds the movement to end Alzheimer's. I'm going to challenge the rest of you - the other half who had not pushed one yet, we've got 15 minutes left on today's call, during those 15 minutes, push 1 and let us know that you're with us in building the movement. And

with that, let's turn to Edith Royal from Austin, Texas. I think we're having a little technical difficulty. Okay. We'll have Edith with us in just a moment. Let me also add that for any of you that are not yet on hold with a question that if you press star 3 on your phone, you can get in the queue to ask a question or make a comment on today's call. We have approximately... A little under 15 minutes left and we'd like to hear from as many of you as possible. We are... We're having a little technical difficulty getting Edith on the line. But, let me see if there's someone else in the queue that we can bring up first and then we'll go to Edith, as soon as possible. Okay. We're going to go to Stanley Terman. Stanley. Are you on the line?

Question: I am. Thank you very much.

Ian Kremer: Thank you.

Question: I'm so glad that you're doing this petition and I think that we have lots to hope for. If we can win with Darfur, we can certainly win with Alzheimer's, which affects so many people. And I would like to say that I'm glad to also see, to strengthen the quality of care and expand support for people who have Alzheimer's Disease and their families, which is your bullet point number 2. One of the ways to increase awareness and to get encouragement is to say that, to approach the solutions in a very broad way, to include the importance of completing advance care planning. Because no stage of Alzheimer's causes more suffering than the advanced stage. And we need to... And people often neglect to include how important it is to encourage, to educate, and to motivate people to fill out an effective living will, which can even prevent, ironically, premature dying. And it's even good for people of faith, who sometimes avoid living wills. So, I think if we include the specifics of not only to prevent the disease, to cure the disease, and to treat the disease better, but also... But even... We're still going to have millions and millions of people reach the advance stage of dementia. And when they do, they need to have previously planned a way that reduces their suffering and reduces the emotional angst of their loved ones and their burdens, and so that they know with certainty, when has that time come to forego treatment that has become extraordinary or disproportionate that no longer can help, that only prolongs the process of dying and that may even increase the risk of further pain and suffering. We can... We have the message to do this right now, what we need is education. And I hope... I think that this as a component of your program might help the petition and the awareness because a lot of people feel that, you know, there'll be drug available but it will take so many years to test it to make sure that it works that may be... may not be for me. Well, this is for me. This is for my family right now, this kind of a plan.

Ian Kremer: Stanley. You make a lot of really important points and I want to thank you for all of your comments. I'm going to pick up on just a couple of items that you mentioned and then we'll turn to another caller, if we got the technical side worked out. The first point I want to make is about that planning for the years ahead. And I think you're exactly right. That's an enormous challenge. We have seen general public awareness of Alzheimer's increase enormously over the last, particularly, like

decade or decade and a half. But, utilization of the available though limited resources has not kept pace. And I think it is critically important, as you said, that we continue to do a better job educating the public about how to cope with the disease while we are on the long journey to ending the disease.

And that relates to the other point that you mentioned that I just wanted to share a brief story about. Very brief. You mentioned the role of faith. And while that is not how everyone will cope with the disease. I think it is an important element of how many people cope with it. And it can either be a sense of comfort and support and guidance or it can fail to be that. And I had a... just by coincidence, an extremely interesting and moving conversation just yesterday with a rabbi from a local congregation in Northern Virginia whose family has not been touched by dementia of any sort, though, a very close family friend has been impacted by the disease. And part of his personal commitment to fighting Alzheimer's is around exactly that issue you described about planning what is within our control at this point in the fight against the disease. So, he is making a personal commitment to counsel families who are interested in taking advantage of his support, counsel families in how to cope with Alzheimer's, specifically from a Jewish philosophical perspective. And I just thought that was fascinating because I think it reinforces the idea that while we know there are 5.4 million Americans who live with Alzheimer's today, who have that disease. We also know there are 5.4 million individual ways in which they will handle that disease. But, for so many of those people, in whatever religious tradition, they are comfortable, that the support and guidance of their faith community leaders and fellow parishioners is indispensably valuable. And that, each individual will see the disease through their own experience... religious experience and otherwise, and we need to respect that we need to be able to support that by engaging clergy across faiths in this effort.

We do have another call... another caller on the line. We're going to turn to Patty Abrego, who was with us a little bit earlier. Patty. Are you still on the line?

Question: Yes. And I just have 1 question now. I loved your idea of copying the petition and keeping it with you. Where would we send signed petitions to if they were... paper... pen and paper petitions?

Ian Kremer: On the petition itself, it gives instructions, that those petitions, we would urge you to return to USAgainstAlzheimer's. Just put them in the mail...

Question: Okay. Great.

Ian Kremer: Send them in and USAgainstAlzheimer's will be in touch with those people to offer them additional information and, as Stanley mentioned, access to other resources to help them in whatever struggles they may be facing today.

Advocacy is so critically important to changing the phase of Alzheimer's, but Stanley and yourself and others are exactly right that, not only do we need to ask people to sign this petition and make their

voices heard to the federal government that change needs to happen now and it needs to be a dramatic change, we also need to give back, we need to support those of you that are facing this disease in being better equipped to face it. Whatever may come next, there are resources available in every community, some communities more than others and we will work to improve access to those resources. But, the first test is to make sure that everyone knows the resources that do exist and has access to them. So, we will act...

Question: That's exactly right. That's one of the things that I did find out in this course, my sister not being a nurse did not know what her resources were that she could get for my mother. I had to guide her along the way. She had the benefit of a home health nurse who knew, you can have this, you can have this, you can have this. Thank you.

Ian Kremer: And so many of the resources are free. And that's really important that the Alzheimer's Association, for example, has a 24-hour a day, 7-day a week, 365-day a year live help line service. And they don't charge a dime for it. Not a dime. So, anyone in the country can call that hotline, day or night, with any issue they wanted to discuss or if they just need a friendly listening ear. A live person who will hear them, share their pain and let them get it off their chest in a safe and confidential environment. And then, also connect them with community-based services, if that's what they need. But, not enough people know that that hotline exists.

So, I just want to take a moment to remind everyone that USAgainstAlzheimer's will be e-mailing out to all of you information after this call with how you can find the petition on the website, a direct link to that petition, as well as a link to where you can download a hard copy of the petition to share in your community. And as Patty said, collect signatures and send them back in to the USAgainstAlzheimer's offices so that more people can be a part of this movement. So, you'll either get that e-mail immediately following this call or within the next few days, depending on how you accessed the call.

We're now going to go back to Alan Arnette for a moment.

Alan Arnette: Yeah. Thanks. I want to really reinforce to the listeners that may think that talking to our government right now is not effective because we all know the issues that we're currently going through. I was... Actually, I was in Congress back in November of last year after I completed my mountain climbs to try to raise awareness for this disease. On a personal note, my mother... And I have 2 aunts who also had died from Alzheimer's. So I met with Senators Collins, Warner, Markey and Chris Smith over a period of about three days in their offices. And when I asked them, "Okay. So, here's what I'm doing. But, what is it that's really going to make the biggest difference?" I was shocked at that the consistency of all the 5 offices that I met with, they all said the single thing that influences the senators and congressmen the most is hearing directly from their constituents.

So, sign this petition with millions of people all saying the same thing. I've read the petition. I'm going to post it on my website where I have a million followers. I'm going to put it on Twitter and on Facebook. I'm going to get it out there as much as I can. I love the idea of printing it out and talking to anybody and everybody that will listen. It's this type of grassroots and this type of energy that is going to get Congress' attention, and then we can go from hundreds of millions to billions.

And George, I love your case study of how the HIV/AIDS investments saved \$1.4-trillion in health care cost after a \$10-billion investment. I mean, those numbers are just astounding. And this is the same thing that we need to do for Alzheimer's. But, you know, it's not only the money, but it's the human toll. And it sounds like a lot of people on this line all have gone through the same thing that I went through with my mother, of going through that journey. And you just feel helpless and at the end of the day, all you can do is hold their hand, give them as much love as possible and try to make that journey as painless as possible. So, I'm behind you 1,000%. And everybody on the line, go out there and shout from the mountain tops, from the grocery store lines, and just to anybody who will listen, to sign the petition and let our government hear from us. So, thank you, guys so much.

Ian Kremer: Thank you, Alan. And beautifully said. I'm going to leave it there with just a reminder to everyone who's on the line. If you haven't pushed 1 on your phone yet, please do and you can leave us a message about how you would like to be involved and we'll follow up to give you more support in that effort.

Thank you again for participating in Alzheimer's Talks. We are grateful for the support of the Zickler Family Foundation that made this call possible. Alzheimer's Talks is a monthly series where we will discuss all kinds of topics from genetics to international coordination to gender differences. I hope that you will participate in these calls and share the information with friends and colleagues. In a few days, we will have a copy of the recording and the transcript of this call on the USAgainstAlzheimer's website for you to share with your friends. And we will also send an e-mail with a copy of the petition that you can share with your friends, colleagues, people in the grocery store and everyone else here that you encounter. People of good heart will sign this petition. Please stay on the line to leave a message with your ideas of how we can increase participation in this petition effort. And again, I thank you and wish you all a wonderful day."