Alzheimer's Talks
The Growing Impact of Alzheimer's on African Americans
A conversation with Dr. Laura D. Baker
April 26, 2013

George Vradenburg: Good afternoon, or at least good afternoon on the East Coast. We have a remarkable 34 states represented on this phone call indicating the geographic breadth of interest in today's topic and today's speaker.

My name is George Vradenburg. I'm chairman and co-founder of USAgainstAlzheimer's and I'm pleased to have everyone on the phone today. As you know USAgainstAlzheimer's represents a group of engaged and enraged individuals who want to change the pattern, pace and urgency of what's going on in the Alzheimer's field today and today's topic highlights exactly why we need a change in the pace and trajectory of the way things are being done.

Today is actually, the introduction of the African American Network Against Alzheimer's. A groundbreaking new initiative uniting the collective voice of African Americans to change the pace of progress in the fight against Alzheimer's.

This call is generously supported by Patrick Berry, a former Washington DC partner in the law firm of Baker Botts and a founding board member of USAgainstAlzheimer's. Patrick took early retirement last year to lead the board's efforts to create the African-American Network and he will assist the network's founders and Stephanie Monroe, the network's director in its implementation and you'll be hearing near the end of the call, at close to 3:00, the introduction of Stephanie Monroe and some more information about the African-American Network.

Today's call is a discussion with Dr. Laura D. Baker on the growing impact of Alzheimer's on African Americans. Did you know that African Americans are twice as likely to develop Alzheimer's disease? And we'll find out today at least some hypotheses about why that's the case. If the United States has any hope of bring an end to Alzheimer's in this decade, we need to better understand this appalling health disparity, how this information can help lead us to a cure as we find out why African Americans have this disease in greater numbers and present differently. We'll learn about whites as well.

During this call, you will hear a description of this problem, possible reasons why Alzheimer's might disproportionately affect African Americans. Some of Dr. Baker's exciting research, including brand new trials on intranasal insulin and exercise for adults with mild cognitive impairment. We'll learn more about her partnership with the Maya Angelou Center for Health Equity and her commitment to increase African-American representation in clinical trials and

ways that you maybe able to participate in some her research. And lastly, she will talk about the importance of participating in clinical trials, particularly for African Americans who continue to be under represented in this important aspect of drug development. Why this is absolutely necessary to understand and ultimately end this health disparity.

So, our speaker today, Dr. Laura D. Baker, she is an Associate Professor of Gerontology and Geriatric Medicine at the Wake Forest School of Medicine. She is also on the affiliate faculty of Wake Forest Maya Angelou Center for Health Equity and she is part of the minority recruitment work group of an important alliance between the National Institute of Aging, an Institute of NIH and the Alzheimer's Disease Cooperative Study which is a system and network of institutions across the country that work together in trying to address Alzheimer's. She will tell us more about the minority recruitment workgroup of the NIA-ADSC during the call.

Remember if you have a question during the call, please press star three on your phone. By pressing star three, you'll be placed into a question queue at which point, we will take questions as they appear in that question queue and when we call out your name, we will unmute your line so that you can ask your question. Please have your question ready to share briefly with a member of our staff and we'll try to get you on the air as soon as possible when we open up for questions.

So, Dr. Baker, we are pleased to have you with us today and we look forward to your opening remarks and then questions that the participants on this call might have regarding your research.

Dr. Laura D. Baker: Thank you George. I'm grateful to be here on this inaugural effort. That's young but I'm very proud to be part of this - as we know in clinical trials that we are kind of in a very important place where it is time to make sure that we meet the needs of all Americans and we realize too that we need to do things in a different way to make sure that happens and so I'm here.

The list that George gave you on the call was a little daunting that we're going to actually cover this in 20 minutes but I will do my best to cover this territory and I realized as we go forward that I will not be able to answer everyone's questions but I have seen some of the questions that have come to me early and I've tried to address those in my presentation, but I just wanted to warn everyone that in a 20 minute period, it's going to be difficult to answer everything but let's get started.

So I am, as George mentioned, here today to talk to you about the link between the high risk of Alzheimer's disease among African Americans and also a little bit about the work that we're doing here at Wake Forest and across the nation to identify new ways to prevent and slow the disease and most importantly, especially for the purpose of this effort that we are all gathered here to talk about is, we are committed as a national coalition of scientific investigators to ensure that African Americans are appropriately represented in these important trials that will help us know how to treat this devastating disease.

So, I mentioned in my introduction, and some of you may know about the statistics but African Americans are 2 to 3 times more likely to develop Alzheimer's disease and this is in comparison to blacks from sub Sahara Africa and compared to adults of European descent which should automatically make you think that maybe environment plays a role in this strong risk. I had an early question about whether this statistic is also true for veterans, who presumably have comparable access to health care across all different races and there was a study conducted in 2005 at the Houston Veterans Affairs Medical Center and they showed similar prevalence rates of Alzheimer's disease for all races with the exception of African Americans which was 50% higher. So, of course this study can't address whether equal access to health care is a moderating or an important variable. It does suggest that it's more than that.

So people want to know how do we know that African Americans have a higher prevalence and thus risk for developing Alzheimer's disease. There have been a number of scientific studies published so far that suggest the rate of decline when you have mild cognitive impairment - just for those who are not aware or sure about what mild cognitive impairment is, in the science world and in the clinician world, mild cognitive impairment refers to a condition that precedes the dementia. And so these people have mild changes in memory predominantly. They are able to carry out their daily tasks just fine but these people who have a memory problem are at high risk for progressing to dementia but these people are not demented, these people with mild cognitive impairment. So, I just always talk about it in terms of the gray zone between normal and dementia and this is just a really important group of people to study because this is the time where we can actually have an impact on prevention. If we wait until dementia occurs, our window of opportunity for prevention is lost.

So, some studies have suggested that the rate of decline among African Americans with mild cognitive impairment is faster than other adults, other races, and whites. But then just to confuse things more, there are a couple of studies that show once dementia is diagnosed, rate of decline among African Americans maybe slower. So, I'm sure this sounds very confusing to you, then we're all on the same page here. But just for this group, it's important to consider some issues that might influence these kinds of reports; and I think it's always important to talk about these issues so that when you read through these reports in the media and scientific journals that you're aware of different findings that occur because of different kinds of variables that were not considered or that were not represented equally in the samples that were studied. So, for example, when we say decline was faster in a group the question you must always ask is how was an impairment diagnosed? Were the tests that were used, did they include racial or culturally biased questions? Is the sample that's talked about in that study, is it representative of the population? Or does it only include those people with relatively more medical problems, maybe only those with other comorbidities like cardiovascular disease or diabetes. These are the people that are coming to the hospital. These are the people who are being diagnosed with a memory problem. So, it's just important to always consider who is the group that's being described in these studies and these are the kinds of issues we have to keep in mind when we're trying to make sense out of what's going on in different populations of people. So the other kinds of issues to keep in mind include, do these people in your sample, do they all have equal access to health care? What about those people who never use health care

and never come in to the hospital? Are we possibly overlooking Alzheimer's disease in that group? And if that's the case, maybe our numbers, and this would be right now, that Alzheimer's disease is 2 or 3 times more likely in African Americans. If it's true that there is a subset of people who do not use health care, are we actually under representing these numbers? So, these are just the kinds of questions that we have to deal with that also contribute to confusing results that you might read in a report.

So, why would this be the case that African Americans are 2 or 3 times more likely to develop Alzheimer's disease? And there's a number of reasons and I'll just point to a couple of them on this call. Cardiovascular disease in general; cardiovascular disease is more prevalent in African Americans. Cardiovascular disease comes with many different medical conditions that have independent risks for the development of Alzheimer's disease and one of these risks, one of these factors, that's part of the cardiovascular disease constellation that has a potent increase of risk for Alzheimer's disease is type 2 diabetes.

Now, type 2 diabetes is an independent risk factor for cognitive decline and dementia. And I'm just going to give you some statistics to give you an idea of how prevalent this condition is and what the implications of this type 2 diabetes will have. If we know the statistics of type 2 diabetes and we know it's a risk factor for dementia. I think these statistics clearly convey the problem that we have in front of us. So, 2 in 10, the 2011 Center for Disease Control estimates indicate that 2 out of every 10 African Americans over the age of 20 have diagnosed or undiagnosed type 2 diabetes, 20% and this translates to about 5 million people, and this is just among adults. For the United States population as a whole, including African Americans, the estimates are only 1 and 10. So, the African Americans are twice as likely to have type 2 diabetes and these statistics, for me in particular, for my group of investigators who study aging, is even more foreboding because we know that over the age of 65, these statistics get much worse. The prevalence of type 2 diabetes for the nation as a whole is 25% of all people over the age of 65. So, diabetes is a clear problem in the United States population. It is a larger problem with African Americans, and aging potentiates or exacerbates this problem for everyone. And the aging component is key here because age is the number 1 risk factor for the development of Alzheimer's disease. So, we have a constellation of risk factors that are all converging that this is setting up the stage here for the challenge that we have before us. Now the other statistic that I'm going to lead you to, and I really don't mean to fill your minds with numbers but I just really want to convey the impact of this problem. So we've got a high incidence and prevalence of type 2 diabetes among African Americans. So, given this next statistic, you can see we're in trouble. Older adults with type 2 diabetes have a 65% chance of developing dementia and those who do not develop dementia still obtain lower scores on test of memory and thinking. So, here we have more diabetes among African Americans, even more so in older adults who are at greater risk for dementia and now among that group, we have a very high risk if you have type 2 diabetes of actually progressing to Alzheimer's disease and dementia. So, I think that always sets the stage for me and keeps me focused on the problem.

I'm looking at the time, so I'm going to move on. We've been studying this link between type 2 diabetes and Alzheimer's disease for many years now and I work with Dr. Suzanne Craft and we

have been studying the link between insulin resistance, change in metabolic function and development and progression of Alzheimer's disease and there are many different mechanisms that we're studying having to do with metabolism, with energy for brain function. We study the clearance of the toxic beta-amyloid out of the brain, this beta-amyloid is the key ingredient of the plaques that are the hallmark plaques of plaques and tangles in Alzheimer's disease. There are far-reaching consequences of this impaired metabolism on Alzheimer's disease.

Other kinds of factors that contribute to this high risk of Alzheimer's among African Americans, I mentioned before has to do with cardiovascular disease, atherosclerosis and hypertension. Hypertension is highly prevalent in African American older adults in particular and these cardiovascular disease risk factors are associated with the development of Alzheimer's disease. They are also associated with development of vascular dementia, but Alzheimer's disease is not left out of that picture.

We are studying the potential impact of genetics. There are large-scale genetics studies going on now to examine genes that predict the onset and rate of progression as well as race differences. So, we'll know more about these studies in the next few years. Someone asked an early question about the Apolipoprotein E gene which has gotten a lot of attention both in the scientific literature and in the public literature and the ApoE gene is, from what we know, is the most consistent non deterministic genetic risk for Alzheimer's disease and we do know that it also increases risk for African Americans but not with the same magnitude as for whites and other minority groups. So, we are still studying this link. It may be that ApoE does not have the same impact on disease development as it does in other groups and thus making the point hopefully about why it's so important to make sure that African Americans are appropriately included in clinical trials. If this ApoE does not have the same impact on risks, it could have implications for treatment and early detection, and without adequate representation by African Americans in these trials, we'll never know that.

So, you know, what does this mean for our communities when we have this higher incidence and prevalence of Alzheimer's disease in our African American communities, we have of course, additional costs for the families and for health care, the family burden. Many many more families are affected, proportionally speaking. This situation sets the stage and prioritizes the need to identify new effective treatments to optimize quality of life for African Americans and their families and then this brings up the whole topic of prevention. This is more prevalent in African Americans, what is the best prevention strategy? Is it the same prevention strategy that might be effective for a different group? It may in fact be quite different. We all know this, if you have any experience with reading about studies in any way, you know that the results of the study can only generalize to the kinds of people that were in the study and we cannot make generalizations to people who are not represented. There had been some hallmark studies over the last 10 years, particularly having to do with what is the standard of care for hypertension treatment and we've had some revolutionary findings to indicate that the best treatment for African Americans with hypertension is not the best treatment for a white or other minority groups. The African Americans in a hallmark trial, what we refer to as the ALLHAT - they found that the diuretics were much more effective in African Americans than the ACE inhibitors, which

is the standard frontline intervention for most adults and has been for the last 25 years. So, this hallmark study raised the awareness that we need to make sure that all groups are represented so we can generalize our results to the groups that were included and this study, the ALLHAT study, has motivated many new concerted efforts from NIA and other coalitions across the nation to make sure African Americans are appropriately represented in trials. And so there's many different issues that we all know about that are obstacles for African Americans participating in trials, having to do with the diversity of the research team, the racial and cultural diversity of the research teams across the nation. We have an unfortunate history of research abuses that we need to acknowledge and make sure that they are addressed to the satisfaction of the participant in terms of education about new procedures that are in place and that we'll protect their rights and also we have relied on folks having to come to universities and hospitals and leave their communities rather than thinking about a model where the research would go to the participant. And I think these are all things that we are trying to shift our attitudes about, our practices, in the interest of encouraging trust, building trust, between different communities. We realized that we have not as an academic community done a really good job at that in the past but there are now national efforts to really try to repair and correct some of these short sightings in the past.

And so I think I better move on to my research now, the work that we're trying to do and how we are aiming to increase African-American representation in our trials. I work with, as I mentioned Dr. Craft, who is a world leader in studying the effects of insulin delivered to the brain using an intranasal, through the nose, delivery device. And so, what we have found was people with metabolic disorders, produces insulin resistance because these people have high levels of insulin in the bloodstream but paradoxically or on the flipside, they have less insulin in the brain. And so this strategy of administering insulin directly through the nose, this insulin gets into the brain, the idea is if we can restore these levels in the brain can we correct some of the metabolic disturbances that promote and possibly cause the development of Alzheimer's disease and the progression of that disease overtime?

And so one of the new studies that we're conducting out of Wake Forest, that will be a national trial, is administering intranasal insulin over a 1-year period of time to people with mild memory problems or early-stage Alzheimer's disease. Various Alzheimer centers across the nation will be participating in helping us enroll subjects into this trial. It's a 1-year trial and month 12 to month 18 will be open label so everyone then will move to the active insulin. It's delivered through a device that's, it's very different but just to give you a visual, it's like an Afrin spray device but it breaks up the molecules into much smaller particles. But this study is the last one that will be conducted, if it’s positive that insulin might be prescribed to treat memory impairments and dementia.

And just very quickly, we also have an exercise trial. I've been studying exercise now for quite some time and we have a new national trial of aerobic exercise. Again, you can see the theme here, is how can we restore metabolic health so that we can restore or improve cognitive function? So, the exercise is a potent therapy strategy to improve the health of many different biological systems. So, we will start a national trial in the next few months using these

Alzheimer's centers across the country to test the idea that aerobic exercise can improve cognition and again, this is supposed to be a trial that precedes new prescriptive practices. Both of these trials are supported by the National Institute of Aging and they both will be conducted through the Alzheimer's disease cooperative study consortium out of University of California - San Diego.

Historically, in clinical trials, minorities have been represented about 12% of the enrollment. We are working with NIA, we are working with USAgainstAlzheimer's, many different coalitions across the nation to change this and these trials and the insulin and the exercise trial and also the A4 trial that Reisa Sperling talked about last month. Our goal, set by NIA, is to enroll a minimum of 20%. So we still need to move to a larger number but it is a mandate for these trials and there are many new strategies in place that are developing and will be in place to ensure that we meet these goals. For the intranasal insulin and the exercise trial, Dr. Craft and I have actually increased those goals. We are both shooting to get a 30% minority enrollment. We will be working with our Maya Angelou Center of Excellence for Health Disparities here at Wake Forest to develop new strategies and we will also be talking with people across the nation with focus groups and calls such as this to change our ways so that we can be more effective at meeting the needs of our African Americans and making sure that they are appropriately represented in our clinical trials that will forever affect standard of care for our patients.

George Vradenburg: Dr. Baker, thank you so very much for that really informative discussion both about causes and about what you're doing with your own work. I am curious. I'll ask a couple questions but remember anyone who wants to ask a question, please press star three on your phone. You'll be placed into the question queue and we'll get to you in just a few moments.

As you know, women also seem to have a disparate impact and I am curious about the intersection of African Americans and women which would suggest that African-American women are particularly exposed to the possibility of Alzheimer's and I just would infer that from the fact that both groups suffer some disparities. Is that true and if so, is there an explanation why women and African-American women might be doubly disparately impacted?

Dr. Laura D. Baker: Well, George your question makes the perfect point of why we need an adequate number of African-American men, in order for us to make that assessment, enrolled in our studies. We don't have the answer to this question and in many of our clinical trials, particularly, clinical trials for Alzheimer's disease, it's the women who tend to enroll. We have proportionally, very few African American men who enroll in these trials and so our ability to you know compare the men versus the women, we're not able to do that and there are trials now in many different areas of research, like kidney dialysis for example, men enrolled because they have to. I mean they're much more represented in those kinds of trials but in Alzheimer’s trials, it's highly disproportionate. So, right now, we really aren’t able to answer that question.

George Vradenburg: Okay. So, there seems to be a related question here in particular based upon your work from Wolf Juekoff from Rexville, New York. Mr. Juekoff, would you like to ask your question of Dr. Baker?

Question: Yes. I was wondering if the nasal insulin would only help people who have diabetes or would it be expected to also help people who have no trace of diabetes who are just regular healthy people who might have causes of possibility developing Alzheimer's? And also if the insulin is expected to slow the progression of Alzheimer's after it has started?

Dr. Laura D. Baker: Okay. Sir you asked some very good questions and some of these relate to a conversation that I was not able to have on this call as yet and that is this, in our studies where we're studying the effects of this intranasal insulin we do not include people with diabetes in these studies. We still need to understand what impact this intranasal insulin might have for people with type 2 diabetes. Now, this intranasal insulin, it changes the insulin levels in the brain but not in the blood stream. These particles that you travel to the sinus membrane are so small that they do not get into the blood stream so, in theory, it should not exacerbate a diabetic condition. However, until we can complete our proof of concept studies to demonstrate that it improves people without diabetes, we have not done those studies. So, right now it is not recommended for diabetes. People take insulin shots in their muscles, in the periphery to treat an insulin deficiency. That's very different from what I'm talking about now. So, we do not recommend this for diabetics right now. We are recommending this for, well, this is what we're studying, we can't recommend it yet, but we are studying the impact of this intranasal insulin for people with mild cognitive impairment. So, these are the people in the gray zone and people with early stage Alzheimer's disease, and so it has nothing to do with diabetes. As we all get older, as we age, all of us, our metabolic efficiency is reduced. So, many of us develop this metabolic disturbance that's referred to as insulin resistance or glucose intolerance as we get older. So, there is just a natural metabolic disturbance that occurs with age and even more so with the onset of disease. This is the condition that we're trying to treat, not diabetes.

George Vradenburg: Thank you very much Mr. Juekoff. Our next question is from Pamela Rivers. Miss Rivers, would you like to ask your question please?

Question: Sure. Hello, Dr. Baker. My question is, I'm African American and my mother had diabetes as well as Alzheimer's and then my grandmother had just Alzheimer's as she is strong, strong as a bull but my question is that I definitely understand the importance of getting people in these trials, minorities you know of all sorts. But I think a big question is, are you looking into who are getting health care in general? Because sometimes that's just the problem within the community of getting people for health care and so if they don't go for health care, there's not going to be the comfort level of trying to get people into trial. So, is this something that you're trying to figure out as well or you're like, you know, are we only focusing on those who are willing to participate in the trials and not deal with maybe what is the bigger picture?

Dr. Laura D. Baker: Yeah. The points that you bring up are just right on target and you're identifying the issues that we are trying to brainstorm using you know leaders across the nation to brainstorm how, what is the best way, how do we deal with this, what is our approach to go to the participants and develop a satellite, a community research clinic where people would come to us within their communities for the research and then in doing so, they would receive some medical care it's still always going to be a selection bias. It's always going to be people who choose to at least come a little bit away out of their home but the point you're making is very, very important and this is one of the facts that we are taking a look at and so, you're absolutely right, we have a lot of work to do and use of health care and willingness to use healthcare has a lot of implications for willingness to enroll into a clinical trial. One's got to precede the other and so, yes, we do have to identify some alternative strategies, something that's not been tried in the last 20 years. So, I don't have an answer for you but I know this is on our brainstorming table.

Question: No, no, problem. Is it something that you think about though? Like is there a way to...

Dr. Laura D. Baker: Absolutely. We fully appreciate that particular selection bias and we realize that in order to get a representative population of African Americans, we have to do something radically different. We can't wait for them to come, use health care resources at a hospital.

George Vradenburg: I'd be curious Dr. Baker whether given the potential environmental factors, not just comorbidities, whether there's any study that you know of which has looked at the geographic distribution of African Americans who have Alzheimer's based upon Medicare data or other data to suggest maybe the rural, urban difference, different food habits, other exposures that might relate in some fashion to increased incidence of Alzheimer's among African Americans.

Dr. Laura D. Baker: It overlaps the demographic prevalence map of type 2 diabetes.

George Vradenburg: And does that show a greater prevalence in what? In rural America, in urban America, in the south, the Appalachia? I mean, what is the geographic distribution of those who are showing a greater incidence of diabetes?

Dr. Laura D. Baker: Well, the demographic maps, you know, the concentration is all in metropolitan areas but you know, is it with a per capita? I don't know the answer to that if you were to adjust for the number of people who live within the certain area. So, that's a good question.

George Vradenburg: I've seen Medicare related data, which would suggest that there is a higher concentration actually in the Carolinas, Virginia, West Virginia, Appalachia area.

Dr. Laura D. Baker: Oh, by state? Yes. We definitely have some states with a larger problem. My state is one of the worst in the country. So, I just relocated from Seattle, Washington and this is one of the reasons I moved here.

George Vradenburg: We had a number of questions both before and there are a couple online who are asking the question, what do you recommend when you see in the clinic someone with mild cognitive impairment and with a concern that they might convert to Alzheimer's. What do you recommend that they do to stave off or reduce the risk or slow the progression of Alzheimer's? What do you recommend as a clinician?

Dr. Laura D. Baker: Okay. So, this is what we do. We do this regularly, we see people with this particular scenario, we reenact day after day here. And our focus is all about lifestyle and being proactive and aggressive about treatment of medical comorbidities. So, we have a conversation about hypertension and control of hypertension. We have a conversation about the lipids, the high versus the low cholesterol profile. We have a conversation about blood glucose levels. Are you monitoring this? Are you high? Is it borderline? A lot of times, our folks would tell us what the doc says, everything is borderline. So, I'm not worried. So we change that conversation and for someone who has mild cognitive impairment, borderline health conditions are not okay. So, we talk about how to make changes and be more proactive using lifestyle interventions to change things and provide some accountability and structure so there's clear goals that these people need to meet. We also had a conversation about stress. What stressors are in this person's life and how to reduce these just at least a little bit, tone it down just a little bit. Because cumulative stress can exacerbate or potentiate a mild cognitive impairment and then we talk about mood and the impact. What is the mood? Is the person mildly depressed? And then we talk about ways to aggressively intervene there, not talking about medications at first but more lifestyle interference. So, depression, mood, hypertension, cholesterol, blood sugar and then we talk about physical activity, how to introduce this in a way that's palatable and not something that you're going to start for 3 months and then quit. So, these are the conversation we have.

George Vradenburg: Remember if you have a question, please press star three and you'll get into the question queue and be able to ask a question of Dr. Baker.

And do you recommend medications and under what circumstances and if so which ones for a person in either an MCI state or very early stage of Alzheimer's?

Dr. Laura D. Baker: You know, I'm hesitant to answer this question. For mild cognitive impairment right now, we have no medications that have shown in clinical trials to be beneficial for cognition. We have trials going on now that will hopefully provide something down the road but now lifestyle intervention is the most potent way to intervene at the stage of mild cognitive impairment. With early state Alzheimer's disease, I am an advocate of do what you have to do, try whatever you need to try. I'm not an advocate of trying things that have not been through placebo control trials, by any means. There are many homeopathic things that you hear about over the internet and I do not ever encourage anyone to try something without a placebo

control trial. That being said, if it's a vitamin with no harm to the body and low cost the risk benefit profile is favorable, I say why not. But, you know, there are some medications for early Alzheimer's disease and it doesn't work for everybody but you know if you happen to be one of those it does help to stabilize the cognitive impairment. You know, to have a blanket statement of no medications are going to work are going to miss the opportunity for that medication to help a few people. So, we don't have a lot of options right now in terms of medications, there are some standard ones out. They don't help everyone but for some, they do. So, my standard recommendation is to recommend a trial if the family is in agreement but it's not a black and white answer on that question.

George Vradenburg: Thank you. We have a question here from Debra Johnson from Elk Grove, California. Deborah, would you like to put your question to Dr. Baker?

Question: Yes. Here is my area. I am a volunteer with the Alzheimer's Association and we are trying to reach out to the black faith community here and one of my questions would be, have you considered reaching into the black faith communities? We have a lot of elderly who are members of different churches and that may be affected with Alzheimer's or you know in the early stages as well as the later stages and if not themselves, there are a lot of caregivers who attend a lot of churches and they may also have a loved one that would be a perfect candidate to participate in your trial.

Dr. Laura D. Baker: That's an excellent idea and I agree with you 100%. And just along those lines, what we are just starting to do here in North Carolina is start a consortium of pastors and community leaders that will come together to brainstorm and figure out how we can do better outreach within the churches and with the pastors playing a role in this consortium outreach effort. So, I think your idea is dead on and in our work-group with the NIA and the Alzheimer's Disease Cooperative Study Unit, we are starting to plan these kinds of workgroups and consortiums and strategies to work through faith-based organizations because with African Americans as you well know that's just a very strong network and this would be most likely a very fruitful opportunity.

Question: Thank you.

George Vradenburg: We have time for maybe one or two more questions and I'm going to ask, I'm going to murder this name, Tigist Hailu from the Penn Memory Center at the University of Pennsylvania. I'm sorry about the name..

Question: It's okay. It's Tigist Hailu.

George Vradenburg: Tigist Hailu. Thank you.

Question: Yes, okay. My question is, I am an outreach coordinator with the Penn Memory Center and I have been focusing on clergy as well and I'm wondering what other strategies have worked for you when it comes to getting more African Americans to be involved in research.

Dr. Laura D. Baker: Well, one strategy that we are just starting to develop is a more of a mobile approach where we are not asking our participants to come to a hospital or to a university but we actually go to their homes or to the community centers within their community and this is paired with education within the community about what is research, how are you protected, why is this important for your community? And that pairing, it seems to just move us through an obstacle that it's not so much a resistance to participate as they didn't know and they didn't trust. And once we can work using that particular strategy and develop and just work on our relationship and trust but also provide education about what is the research, why is this important for me, how does this help my grandchildren and not expecting them to come to the hospital. It's that triplet. It has been just one of our strategies.

Question: Okay. Thank you.

George Vradenburg: And I think our last question today, Amy Duffield from Cary, Illinois. Amy, would you like to ask your question?

Question: I was wondering what your thoughts are on the prescription nutritional supplement Axona for treatment for those with Alzheimer's and also if you know of anyone who has studied the risk of corticosteroids. Corticosteroids can cause diabetes and therefore it seems like it would be a logical thing to study their risk for people, if they're a risk factor for people to get Alzheimer's. So, I was wondering about both of those things.

Dr. Laura D. Baker: Yeah. Those are good questions. I think I saw one of your questions that came through earlier. Axona, I'm sorry, I'm going to have to disappoint you. It's not my area and I don't feel comfortable commenting on that. Sorry about that.

Question: That's okay.

Dr. Laura D. Baker: With regard to the corticosteroids, we acknowledge as a scientific community, we acknowledge that cortisol and stress response is a key component and could very well be a predictor about who progresses or who progresses quickly and who doesn't or who develops it and early versus late. So, change and stress hormones have been a big focus for many years. There's some symptoms associated with the corticosteroid related dementia that don't show up in Alzheimer's disease and so it makes it very difficult for us to draw the parallels. In corticosteroids dementia, you oftentimes get a lot of delusional thinking, which you do not get in Alzheimer's disease in early stages. You get a lot more apathy and you get much more severe mood disturbances, frequently, and these do not occur with the same frequency and the same severity with Alzheimer's disease. So, I think they are separate but I agree with you that in our assessment of Alzheimer's disease and what's going on and what are the perpetuators of decline, the stress hormones are key and I think we are learning that there's certain groups like people who have post traumatic stress disorder may be at higher risk of developing Alzheimer's pathology down the road. So, I think this is still an area that got a lot of attention about 20 years ago and then we had a break about looking at this potential contributor and now, it is again in

the limelight because of new findings relating PTSD to increased risk of Alzheimer's disease. So, I'm in agreement and we definitely need to understand this a little bit better.

Question: Thank you.

George Vradenburg: Thank you very much of your question and we're going to move on but there is some people still left in the queue but I think in looking at your questions that we have gotten Dr. Baker's view on them. So, hopefully, you've gotten your question answered. And Dr. Baker, I want to thank you so much for being with us today.

I'd like to introduce to you and to the folks on the phone, Stephanie Monroe who is the Director of our African American Network Against Alzheimer's. She's a 25 year veteran of Capitol Hill. Having served much of that time as a Senior Adviser to the Senate Committee on Health and Education and she now directs the efforts of our newly introduced African American Network Against Alzheimer's. So, Stephanie, could you say a few words about what we're trying to do with this network?

Stephanie Monroe: Absolutely. Thank you George and thank you so much Dr. Baker and all of the participants on this call. You know as we stated earlier, African Americans are incredibly over affected by Alzheimer's but are very underrepresented in research to find a cure.

Alzheimer's is the 6th leading cause of death for all Americans and in fact the 4th leading cause of death for older African Americans. In addition to having significant health impacts, there is an economic impact of the disease on the African-American community, which is already significant and continues to grow as we age. African Americans who have to leave the workforce, or make a decision to leave the workforce, to care for an afflicted family member lose on average more than $300,000 in earnings, in pension and in social security benefits and are more than 3 times as likely to live in poverty as similarly situated white Americans. So, this is a critical issue that we need as a country to address.

The African American Network Against Alzheimer's is being convened to bring together the collective voice of African Americans to do two things. One, is to change the pace of progress against Alzheimer's by demanding an increase in funding and focus on research on fighting the disease and it's disparate impact on African Americans. And then secondly, to enlist an army of African Americans who will lead communities to take personal responsibility for the solution by enrolling in clinical trials, prevention registries, and also speaking out.

So, today does represent the first official activity of the network and we're very excited about this activity and about our ability to inform and enlist the support of not just African Americans but all who are concerned about the plight of this disease on African Americans, on women, and on our society in general. We are planning and look forward to many more opportunities to educate and engage all of our communities around this critical issue and in fact have also formed a pastoral council against Alzheimer's to enlist the support which is vital in the faith-based community to speak out on this issue.

If you want more information, I would invite you to go to our website which USAgainstAlzheimers.org and click on the African American Network. Or if you'd like to reach out to me directly for more information to find out how you can become personally engaged or engage your community in our efforts. Please feel free to e-mail at smonroe@usagainstalzheimers.org. Thank you.

George Vradenburg: If you'd like to receive more information about the African American Network Against Alzheimer's including how to sign up, just press one now as we complete the call and Stephanie will be in touch with you next week. Remember, for information, please press one now and Stephanie will be in touch with you next week.

Thank you again for participating in Alzheimer's Talks. We are grateful for the support of Patrick Berry, whose own experience with Alzheimer's is described in his published novella, *Escape from Enchantment*.

And we would like very much to thank Dr. Baker for being with us today and exposing us to her thinking and her research and her experience on how to deal with this most challenging issue.

In about a week, we'll have a copy of the recording and a transcript on our website for you to share with your friends, including links for more information on some of the work that Dr. Baker spoke about today.

I hope you can join us for next month's call - Friday, May 17th at 1 PM. Dr. Jill Goldstein will be discussing why Alzheimer's also disproportionately affects women and what research is being conducted on sex-based differences in the Alzheimer's field.

Again, please stay on the line if you'd like to leave us a message with a question or comment and please press one now, if you would like to hear more about the African American Network Against Alzheimer's. So, thank you all very much for participating today and Dr. Baker thank you so very much for spending time with us.