

## Alzheimer's Talks Transcript

### The high cost of Alzheimer's and the disproportionate impact on African Americans

with Dr. Darrell Gaskin and Stephanie Monroe

February 24, 2014

**George Vradenburg:** Welcome to Alzheimer's Talks, this is [George Vradenburg](#), Chairman and Co-founder of [USAgainstAlzheimer's](#) of which the [AfricanAmericanNetworkAgainstAlzheimer's](#) is a critical element as we try to mobilize people around the country to get much more involved in this movement and to speak up, speak out, not be afraid to talk about the disease and to talk about its deep impacts on so many elements of our society.

We have people from 20 states registered for this call, others are calling in. It is a particularly exciting and interesting time in the Alzheimer's movement. [The G8 held its meeting in December in the UK](#) and committed to the American goal of stopping this disease by 2025. Just a couple of weeks ago the [Accelerating Medicine's Partnership was announced by NIH](#), 10 pharmaceutical companies and USAgainstAlzheimer's, the Alzheimer's Association, \$130,000,000 devoted to finding some biomarkers of this disease on which we can test drugs and to develop new targets for the disease. Just last week, USAgainstAlzheimer's announced the [Global Alzheimer's Platform](#), which is a new effort to shorten clinical trials by 2 years globally. So this is a time of great activity, great attention, great focus on this disease but too little time and attention has been given to the disparate impact this disease has on minority populations.

And today we are fortunate to have [Dr. Darrell Gaskin](#), the Deputy Director of the Center for Health Disparities Solutions at John Hopkins Bloomberg School of Public Health. Dr. Gaskin co-authored a report issued this fall entitled [The Costs of Alzheimer's and other Dementias for African-Americans](#). Today he will share with us some of the reports key findings. I just want to note that report was issued on behalf of the AfricanAmericanNetworkAgainstAlzheimer's.

Stephanie Monroe, Director of the AfricanAmericanNetworkAgainstAlzheimer's will, following Dr. Gaskin's remarks, give us an overview of some of the work the network is doing including encouraging participations by minorities and clinical trials.

Today's call is made possible by the generous support of the Zickler foundation. We are so grateful for their support so that we can have this important conversation with you today.

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

Dr. Gaskin, thank you for joining us today. We look forward to your remarks.

**Dr. Darrell Gaskin:** And thank you George for that very kind introduction. Alzheimer's disease and other dementias, is a very important issue in the African-American community.

In addition to being a professor at John Hopkins University for the last 20 years, I've been also the pastor of a church in Washington DC, Beth Shalom A.M.E Zion Church. And one of the common testimonies and prayers in the black church is that you hear our elders say I thank God that I'm in my right mind. And this is a real sense and acknowledgement that we know that diseases of the mind are certainly a possible threat to our own person and livelihood. As pastor, I've seen persons go from being very active and vibrant members of the church to having problems with their short term memory and then having really just that blank stare that comes with not really feeling, being acquainted with one's surroundings and knowing one's self and knowing one's family. And I'm particularly reminded of a person who was very dear to me was the wife of one of my presiding elders. And during his funeral, someone walked up to her and said I'm sure you know me and she looked at the gentlemen and said sir I'm sorry, I don't even know myself. Speaking to the real problems that Alzheimer's disease causes for African-Americans.

As you had said, African-Americans bear a disproportionate share or portion of the burden of this disease. I was asked to look at the cost of the disease, so while African-Americans make up 13% of the population, they bear a third of the total cost of Alzheimer's disease and dementia in the nation something to the tune of 71 billion dollars. And most of that money is being borne by the families and of African-American women with Alzheimer's and half of that cost is concentrated in the South. The major portion of that cost is what we call unpaid hours for caregiving because for anyone who has had a relative that suffered with this disease, I do know that what that does, it places demands on family members to provide caregiving to watch out, to help persons with their activities of daily living, bathing, eating, dressing, and those kinds of things, and that you really can't leave persons who have this condition alone for long periods of time. And so, 61% of that 71 billion dollars is just the value of unpaid caregiving hours.

And to give you a concrete example, another one of my colleagues in ministry used to be a very active elder building churches throughout the Philadelphia area, his wife was very active in

ministry. Unfortunately for him, he was diagnosed with Alzheimer's and began to lose his ability to really be active in ministry. But that not only affected his ministry, that also affected her ministry because all the things she was doing as part of the church, all came to a stop because she would have to now take care of him. And so not only do we miss seeing him during our usual meetings, we also miss seeing her because she is very much involved in taking care of him. So unpaid hours for caregiving is a significant portion of the cost of care. As I've said, 43 billion dollars annually. And then, in addition to that, there's also care that's being provided for nursing home care as well as care for medical services, that's 21 billion and 5.5 billion dollars respectively.

We also note that early on-set Alzheimer's affects persons in that 40 to 64 age group and when that impacts them they're unable to work and so not only does that mean that they have to withdraw from the labor market but it means that their family miss the needed income that would come from their labor and then also society misses the resources that they would provide in taxes. As I said earlier, the distribution of these costs are concentrated in the South, 49% of the costs are in the South followed by the Northeast with 20% of the cost. And 61% of these costs are borne by women. And so it is a significant cost to the African-American community.

And one of the reasons why we see the disparity is because there's such a big disparity in cognitive impairment by race. So African-Americans compared to white non-hispanics are three times more likely to have cognitive impairment between the ages of 55 and 64, between the ages of 65 and 74, they are five times more likely to have cognitive impairment. And then when we get to 75 to 84, it's over three times more likely to have cognitive impairment. And so its that disproportionate share of the burden of the disease that really impacts and causes, the cost data that we're seeing and that's what's really driving the disparity in cost.

I want to say that while we have, in a real sense, placed a dollar figure on the cost of Alzheimer's and Dementia at 71 billion dollars today. As the population becomes increasingly more minority, by 2050 we expect the United States could be what some call a majority-minority nation in the sense that we'll be a plurality in which no group would actually constitute over 50% of the population. That means that if we don't get a handle on Alzheimer's disease in the African-American community, these costs are going to balloon and so we see that as we moved from 2012 to 2050, the annual cost go from 71 billion dollars to 145, 146 if you're rounding up, billion dollars in 2050.

So I wanted to remind you, while we have placed a monetary value on the cost of Alzheimer's, we recognize, how do you put a price on memories? how do you put a price on being able to sit down and have a conversation with a loved one or friend? It's very difficult. One of my colleagues Dr. LaVeist was relaying, his mother, during the end of her life, she suffered with

cognitive impairment and he would go and visit her and sometimes she would not know who he was and she would mention to him, during the visit he would say that he worked at John Hopkins University and she said oh yes, I have a son that works there and then she would talk about him to Dr. LaVeist. And he had to come to accept that this was the kind of relationship that he was going to have with his mother in her latter stages of life. And it's unfortunate as a society, we have come to in some ways accept that because we haven't really put the kind of resources that we need to try to understand this disease better so that we can have medicines to treat this disease.

So I think, hope, and pray that one of the outcomes of this particular study, will be by highlighting the cost of the disease to the society at large, it'll help us reevaluate what we're spending in order to understand how the disease operates, how it works and then how to properly treat the disease because while we have focused on other conditions and spent significant resources on things like heart disease and cancer, if you compare dollar for dollar those diseases impact on society and Alzheimer's and other dementia's impact on society, we're not nearly making the investment that we should.

So I appreciate your willingness and your desire and your interest in this study and I certainly will be happy to answer your questions.

**George Vradenburg:** Thank you so very much Dr. Gaskin for the description of your study and we'll open for questions in just a few minutes. Reminder, if you have question during the call, please press star 3 on your phone. By pressing star 3, you'll be placed into the question queue, have a question ready to share briefly with a member of our staff and they will try to get you on the air live as soon as possible when we open it up for questions in just a few minutes.

But I would like to introduce Stephanie Monroe, the dynamic young leader of our AfricanAmericanNetworkAgainstAlzheimer's for a description of what we are engaged in and she is engaged in leading in terms of recruitment of minorities and particularly members of the African-American community into clinical trials. Stephanie?

**Stephanie Monroe:** Well, thank you George especially for calling me dynamic and young, I really appreciate that, that makes my Monday. Yeah, this is a yeoman's effort, I think, that we are spearheading on behalf of the voices across America of African-Americans. Those who have the disease, those families who are caring for those with the disease, those who are perhaps living in fear that they may develop the disease and those who really believe that we need to devote the right kind of resources and attention to make sure that we don't lose generations of individuals and memories as Dr. Gaskin referred to, by a disease that we believe is completely preventable and treatable if the United States has the will to put the investments in to end it.

And so the African-American Network led by some truly dynamic individuals, Reverend Al Sharpton and Honorary Chair Dr. David Satcher, a former Surgeon General of the United States. Mrs. Kay Coles James, a wonderful woman who has served in several different administrations at the state and federal level, and Melody Barnes who worked with President Obama as his Chief Domestic Policy Adviser. These individuals are helping us to put together this network to get the word out and we are working in communities throughout the country to do just that, to provide individuals with the resources that they need to be able to stand up and speak out so that we can in fact overcome this disease.

One of our significant priorities this year, in addition to getting the word out and empowering individuals to speak to their legislator about the importance of these research dollars, is to make sure that as we drive new dollars to research that in fact we have sufficient numbers of minority populations, including African-Americans, who stand ready to participate as part of that research team going forward. We know that drugs are really important and that the only way we're going to have a cure or an effective treatment is if we are able to move the drug improvement process along. And we need African-Americans and Hispanic-Americans and women and men and all folks to raise their hand and say that they're willing to participate in these trials.

Unfortunately, that's a bit of a heavy lift with respect to the African-American community, the Tuskegee study I think has stifled our ability to really have the type of enthusiastic involvement that we need. And so we are working hard to spread the word through communities about how absolutely essential it is for individuals to participate. We need healthy individuals, we need individuals who have Alzheimer's, we need individuals as I said before from all walks of life. And I would hope with us being at about 14% of the population that about 14% of the participants in clinical trials would be African-Americans. And unfortunately that number trails behind, closer to 3 to 4%. And so that's a big lift but we are working with wonderful research organizations, working with wonderful people like Dr. Satcher to get the word out on the importance and the safety and everything that's been put in place as a result of some unfortunate incidences that happened in the past to make it really as safe as possible for individuals to participate.

And we're going to use every mechanism that we have, we're going to use you know traditional, going out and I'll be doing presentations throughout the country. We're going to use drama through a play that we are working with Garrett Davis on, called the Forget Me Not play, it's a wonderful gospel drama, we'll be taking that into the communities. We're going to use lunch-time seminars for physicians and for individuals in leadership positions and state and local government. Again, we're going to use every resource that we can to get the word out on how absolutely important it is for individuals to both stand up and raise their hand and be part of the solution to this problem.

So we're excited, we know we've got a lot of work to do and we need lots of partners to join us.

**George Vradenburg:** Thank you very much Stephanie. It's quite important, if we don't do research across the gender and racial communities, we're not going to know whether or not this disease has a different course, in different elements of our community. And drugs aimed for simply a white male audience may not work effectively or it may even have adverse consequences in minority audiences or minority populations and among women. So getting, women and men, blacks and whites, hispanics into these trials so that we get a full presentation of the population of America and make sure the drugs that we do develop, the new medicines that are developed, are developed with all of us in mind is critical. That, in a sense is why we call ourselves USAgainstAlzheimer's because it's all of us, it's not just one or two or not just one organization, it's all of us that we have to get in against Alzheimer's.

For those of you who are in the Washington area and I know only a few of you are, [Dr. Satcher had an op-ed in the Sunday Washington Post](#) where he did talk about precisely this issue and the importance to the African-American community of overcoming the history of Tuskegee so that in fact we do get medicines that work in the 21st century and against this devastating disease for the African-American community. So we have a questioner on the line and I'll turn now to Frederick Lowe of the North Star News and Analysis so we do have a member of the media with us today. Welcome Mr. Lowe.

**Question:** Yeah, thanks for having me on the line. Why is it that African-Americans have such a high rate of Alzheimer's disease? What is going on? I mean if we're 13% of the population, why is it such a high number? Is the number in the south, why is the high figure in the south? What are the figures for the other parts of the country? Is it the environment or foods or what's going on?

**Dr. Darrell Gaskin:** Well, I think that the short answer is that we don't know in a real sense the studies have yet to really be done. And some of it has got to be the social determinants of health living in a communities with concentrated poverty, growing up in communities with concentrated poverty, but I think in a real sense and after I did this study, I was really surprised to know that when we think about the priority conditions that we look at with regard to minority health in this country, Alzheimer's disease is not listed among the priority conditions. And I think rightfully we have to focused on heart disease and hypertension and diabetes but this is one that we should also focus on too.

**Question:** Well, let me ask you, is it mostly in the south that Alzheimer's is the strongest among the African-American community?

**Dr. Darrell Gaskin:** No, no, one of the reasons why the costs are concentrated in the south is because a very high percentage of African-Americans live in the south and then also even

amongst persons who live in the north or in other parts of the country, they tend to come back to the south when they retire. And so a higher percentage of older African-Americans live in the south and that's what's driving the geographic connection.

**George Vradenburg:** Thank you very much Mr. Lowe.

I know that you've mentioned that Alzheimer's has got about 2 to 3 times the prevalence in the African-American community when compared to non-hispanic whites, you must have mentioned non-Hispanic for a reason, so what is the relative prevalence of Alzheimer's among Hispanics and non-hispanic whites?

**Dr. Darrell Gaskin:** That I'd have to, to pull up. We know that the condition has a higher prevalence among Hispanics but I don't have that data right in front me George. I have to look that up very quickly.

**George Vradenburg:** I think that the statistics are that Alzheimer's is one and a half times more prevalent among Hispanics than non-hispanic whites. It's three times for African-Americans so there's something going on, that's either racial or environmental or a combination that is driving higher prevalence numbers in the minority community more generally. I do not know what the relative prevalence numbers are with respect to Asians which would be an interesting question but I don't know that I've seen those numbers. So I don't know whether there's a differential there between whites and Asians.

So now I think Amy is on the line and Amy if you might pronounce your last name, I'd be impressed. But from UT Southwestern which is one of our really significant Alzheimer's centers in the south. So Amy you're live now.

**Question:** Hi, thank you. Yes, Amy Zarate, my full name is Zwierzchowski-Zarate. I won't make anyone listen to that because I'm out here at UT Southwestern at our Alzheimer's disease center and we echo what the panelist said about seeing less involvement from minorities in our clinical trials. And so I was wondering if the panel could make any suggestions about things that we can do as outreach efforts or otherwise to try and gain more involvement from the minority community in to our research trials.

**Stephanie Monroe:** Sure, thanks for the question. I was recently looking at a poll that had been conducted by [Research America](#) and they did a nationwide poll and they ask people, what would it take for you to participate in a clinical study? And African-Americans, Hispanics, Asians, people from all walks of life were, when asked this question, I think that the polling was a little bit higher for African-Americans in response but the response was, if our doctor asked us to. And so it seems that doctors, primary care physicians, are really the ones that need to take the lead on asking their patients if they're interested in research studies. And the way we make that

happen is to make sure that physicians locally are aware of the great work that's being done in these various research institutions and that it's, you know very user friendly in terms of allowing them to access information about those trials so they can determine which of their patients might in fact be eligible. But that really is the key, the doctors aren't really asking and that's where I think we need to go. Of course we do, also want to make sure that patients are equipped at the grassroots level of information and so churches can be extremely important, different networks of individuals, care centers and things like that. But my bet would be really to focus on the primary care physicians as being the first line of recruitment.

**Question:** I love that suggestion. I hadn't thought of that. That's really great. Thank you.

**George Vradenburg:** All right, sure Amy. I would have come to UT Southwestern for good ideas on how to get greater involvement of the Hispanic community.

**Question:** Yes, and I'm very new to the department so there are a lot of efforts that we've got going on currently but we're just not seeing a lot of involvement from the African-American community. And so we want to try and increase that and we've got a few ideas up our sleeves but definitely sounds like you guys have done a lot of leg work on it too. So I really appreciate your insight.

**Dr. Darrell Gaskin:** And I will just add that trust is really important and trying to build trust in the community and develop a long-term relationship. And so if you just go out and talk to the primary care providers and just give them a sense that you want to work with their patients but you don't really want to work with them, you're not going to get referrals. If you involve the primary care providers in your work, your research and you give them an avenue on which to contribute, I think you'll be a lot more successful because then they'll feel like they're part of what you are doing, you've developed real trusting relationships. And they'll know that if they send their patients to you, that you'll take good care of them and I think that's really a major barrier that keeps patients from participating in trials.

**Question:** Thank you, that's a really great suggestion.

**George Vradenburg:** Thank you. So Dr. Joyce Simons is on from New York. Dr. Simons? You're live, Dr. Simons.

**Question:** Hello. I am thankful that you took my call and my question to you is how you can get information about African-Americans and the prevalence of this disease with African-Americans onto media like PSA announcements, commercials, print media, because I notice there's a lot of attention to cancer. There's a lot of attention to diabetes, high blood pressure but I don't see anything that relates to it. And as far as Alzheimer's, we need to specifically relate to it in the African-American community. How can you get that information out there?



**George Vradenburg:** Stephanie, have some thoughts?

**Stephanie Monroe:** I think that's a great point and I think that's where you know, speaking to members of Congress can be really important as well as people at NIH and NIA, National Institutes of Health because they are sort of the guardians of the list of those diseases that are considered you know disparate impact diseases. There's other organizations that provide that information and so we're speaking out, we're sharing with them this information and you know there has never been really a focus on the fact that African-American are so disparitly impacted. And so sharing that information is really critical and we can do that in each of our communities to make sure that people are aware of it and the way for us to be able to get increased dollars and increase the attention to the cost of these disparities will be first the recognition of that fact that there is such a disparity.

**Dr. Darrell Gaskin:** Yeah, the other thing I would suggest is that sometimes we stigmatize diseases of the mind so that we don't talk about them, when family members develop them, we don't share them with other people and as a result, you know people sort of suffer in silence. They just, they disappear, the people just say, well I'm taking care of my mother or I'm taking care of my father but we don't know necessarily say why. And if we can, in some ways destigmatize the disease itself, then we can really, be as effective as some of the other advocacy groups for diseases because then, when someone says their love one had a heart attack, they don't mind sharing that in public and saying it and then advocating for it. If someone feels that their grandfather is getting forgetful, then they don't necessarily share that in the same way.

**George Vradenburg:** Yes, excellent point.

Again, just a reminder to people that if you have a question, hit star 3, you'll be put into a question queue and we'll get you on the air as soon as we can.

I will ask a question Dr. Gaskin and that is how do you think or how best do you think we should conduct research in order to understand why there's such a disparity in prevalence between whites and blacks?

**Dr. Darrell Gaskin:** Well, I think, I think we need to do both longitudinal studies where we look at people in mid-life and follow them over time and watch how the disease progresses and to be able to do some of the things that have been done to understand the risk of heart disease and cancer the other is that obviously we need to do more studies looking at some of the genetic biomarkers and how they interact with environment. Many of the people who are contracting Alzheimer's today, are perhaps persons who grew up in circumstances that were quite deprived and were not afforded the kinds of early childhood education that might have been useful in trying to help develop the brain in the way in which it should be. But it's certainly

going to take both some laboratory studies but also some longitudinal studies to actually follow populations to look at.

**George Vradenburg:** I think you're exactly right, the Alzheimer's disease neuroimaging initiative, which is a longitudinal study, is very heavily oriented to educated whites and so actually getting more minorities into the Alzheimer's disease neuroimaging initiative and that longitudinal study, I think is that really interesting and good idea.

So now we have on the line, Cassandra Davis from Gary, Indiana. Ms. Davis, what's your question?

**Question:** I have an interest in studies and I have expressed that to my mother. My mother has advanced stage Alzheimer's, she's in Gary. I have expressed concern for studies to her neurologist and the response that I get back constantly is that there is nothing available or nothing that has been proven beneficial. And then I've also gone online and sought out studies myself and nothing ever comes up in my area but I do have a concern that if a study did come up, would it mean that she possibly could get a placebo because my mother, you know at the point where we would not want to risk her getting no treatment.

**George Vradenburg:** Well, the answer is, if she gets into a clinical trial, she would be randomized and have a 50-50 chance of getting the intervention and a 50% chance of getting the placebo. But I would urge you to consider if you do in fact find a trial that's appropriate for your mother in your area, a 50% chance is better than none. So that I would still urge you to involve her in a trial if there is one appropriate to her stage of the disease in your area. But you highlighted a particularly vexing question and that is, that not every city in the country has an institution that participates in these clinical trials. And as a consequence, there is a heavy concentration of clinical trials sites in major cities around Alzheimer's disease research centers or Alzheimer's disease centers but not in, my guess is from your description in Gary, Indiana and, probably the nearest one would be somewhere in Chicago and that's, while it's not across the country, it's inconvenient... the child or family that is otherwise working to get their family member to a clinical trial in another city or, in your case in another state. You really raise a troubling question and that is how it is that we can more broadly distribute clinical trial sites across the country in a manner that would permit more of the population to participate. So it's a good point. Thank you for raising it.

**Question:** Thank you.

**George Vradenburg:** Our next question comes from, from Penn Memory Center at University of Pennsylvania. Would you please ask your question?

**Question:** Hi, name is Tigist Hailu. I'm the Coordinator for Diversity in Research at Penn Memory Center and I do a lot of a recruitment, education outreach, within the Philadelphia community to get more African-Americans to, basically to get more awareness about Alzheimer's disease and help them understand the importance of research. And one question I always get from audience members is, they always say we're at risk for a number of diseases, heart diseases, diabetes everything so why should we put Alzheimer's disease on our list of priority. So why should we care so, I just wondering how you guys would answer that question?

**Stephanie Monroe:** Well, I would answer it this way, I mean Alzheimer's disease is the only disease in the top 10 where there's no disease modifying cure or treatment unlike prostate cancer and cancer and again we're not competing with different diseases but we've made a really effective investment in those diseases. And as a result we have effective treatments and we don't for Alzheimer's. Alzheimer's is a disease that continues to grow exponentially every year. It's also, it's the 6th leading cause of death for all Americans and it is the 4th leading cause of death for African-Americans, more than diabetes and many other diseases. And so we really need the same type of attention paid to this disease as we have to all others and I think that's the only way that we defeat it.

**Question:** Okay, thank you.

**George Vradenburg:** And I would also note that in fact not every segment of the population is at the same risk. This disease's primary risk factor is aging. So we're looking primarily at populations over 65. So that, if in fact you don't have cancer, you don't have diabetes, this is the more likely disease that you're going to get as you proceed through your decades after 65. So I would suggest that's where we ought to be looking is where the risk is in the population.

We have a question coming from Robin Casten at Thomas Jefferson University, Ms. Casten.

**Question:** Hi, how are you? Thank you very much. I actually do research in MCI, Mild Cognitive Impairment. My question is that, now that we know something about risk factors for Alzheimer's disease that can be controlled, things like diabetes and hypertension, I was wondering if there are any plans to target public service announcements or preventative intervention to younger African-Americans as a way to educate them about what they can do now to perhaps delay the onset of Alzheimer's disease.

**George Vradenburg:** Stephanie, you want to take that?

**Stephanie Monroe:** Well, I think that we have indicators of things that we think contribute potentially. But frankly there's not been enough research that we can say definitively what it is that's causing Alzheimer's, what it is that we should be preventing. I mean we know that eating healthily and exercising and keeping your brain active, that's great, that's good stuff. And you

would hope that that would impact Alzheimer's but we frankly haven't had enough research and we certainly haven't have research directing, you know specific populations like African-Americans or Hispanics, to know whether that really is going to be effective. So, I can't answer the question about public service announcements but I can say that we really need to focus I think on understanding and there are trials that look, are looking at ways to preventing Alzheimer's disease because we know that this disease can lay dormant and can really begin in people 20 years before they begin showing symptoms of it. So we really need to understand a lot more about this disease.

One example that I am often reminded of, we understand generally what causes high blood pressure in individuals. But it wasn't until we really dug into the treatments that we realized that African-Americans respond very differently to the traditional treatments. For African-Americans, the water pills work well and they don't for other populations. So there's something there that's different and we need to understand what's difference so that we can in fact find a remedy and find a cure and then absolutely we should be talking to people about what they should be doing but keeping your mind healthy, eating well, exercising, being alert, that's a good medicine for everyone regardless of whether or not they think they might get Alzheimer's.

**Question:** Good point, thank you very much.

**George Vradenburg:** Mr. Lowe of the North Star News and Analysis has a follow up question. Mr. Lowe?

**Question:** Yeah, I wanted to find out about the trials. When did the trials start? How many cities are the trials in, how many people do you need, African-Americans to participate in the trials and also I have a question for Dr. Gaskin. He keeps on mentioning his study, what's the name of the study and what was the upshot of the study?

**George Vradenburg:** You like to take the first question Stephanie, the number of participants in the A4 trial and studies?

**Stephanie Monroe:** Well you should know that there lots of different trials that are being conducted as we speak throughout the country. You can go to [clinicaltrials.gov](https://clinicaltrials.gov) and type in what you're interested in and all of these trials will pop up.

We are specifically focused on a prevention trial that's going to be starting, they're starting to get all of the research institutions approved and that's the prevention trial that will be taking place in about 65 institutions throughout the country. They ultimately need 1,000 research participants, we need to screen about 10,000 individuals to get to that number. They have a goal of having 20% of the individuals who participate in that trial to be minorities. And so you know, it doesn't sound like a large number but I would like to screen, have about a thousand

people say that, you know they're willing to at least be screened in the United States, a thousand people who are African-Americans throughout the country to say that we're willing to be screened for this. So that's an example and you know shortly they'll be a website that will exist called the A4 Study and you can get more information at this time by going to the ADRC website, the Alzheimer's Disease Research Consortium website to get information on that particular....

**Question:** You need to screen 1,000 African-Americans or 10,000 African-Americans to get 1,000?

**Stephanie Monroe:** We need to screen 1,000 African-Americans to get to a 100. We need to screen about 10,000 Americans to get to a thousand. I believe that's correct.

**Question:** So you need a hundred African-Americans to participate in this study nationwide?

**Stephanie Monroe:** That's right, yes.

**Question:** And these institutions are they hospitals, universities or what?

**Stephanie Monroe:** Variety, research institutions and hospitals throughout the country. And there's a list, if you go to the ADRC website, the list of all the participating research institutions is there.

I'll let Dr. Gaskin answer the question about his study but I can say that, if you're interested in reading the full report, if you go to the AfricanAmericanNetworkAgainstAlzheimer's, type that in, our website will come up and on the front page of that website is the full report on The Cost of Alzheimer's Disease. And so his report is placed prominently on the landing page of the website. Dr. Gaskin?

**Dr. Darrell Gaskin:** Yeah, the name of the study is The Costs of Alzheimer's and Other Dementia for African-Americans. It was commissioned by USAgainstAlzheimer's for the AfricanAmericanNetworkAgainstAlzheimer's. We released it in September of last year at the Congressional Black Caucus meeting. And it was conducted with myself and my colleague Thomas LaVeist at John Hopkins, and Patrick Richard at Uniformed Services University. And what it does, it basically looks at the impact of Alzheimer's disease on both medical and long term healthcare costs as well as labor market costs and then the cost to families. And as Stephanie...

**Question:** How many people, how many... your study, what did you do? Did you... this is, you're looking at medical cost, right, so are you, did you go out and interview people or how does this happen?

**Dr. Darrell Gaskin:** So the way in which we were able to estimate medical costs is that, there's a national survey called the Medical Expenditure Panel Survey, which is conducted by the Agency for Healthcare Research and Quality and the National Center for Health Statistics. And what that study does is to ask a sample of over 30,000 adults about both their health conditions, their labor market outcomes in terms of the wage and how many hours they work and so forth like that. And then also has detailed information on their healthcare costs. And so we're able to observe persons in that survey that have been diagnosed with Alzheimer's or some other cognitive impairment and then look at their medical costs, their labor market outcomes and generate an estimate for how much that's costing as nationally.

**Question:** I guess that, the final question, you really don't know why it's growing so dramatically within the black community. It's cause might be poverty?

**Dr. Darrell Gaskin:** Well, we don't know why, what's driving the disparity in prevalence. And we do have some hypotheses as to what that might be. And, you know, the social determinants of health and particularly not just at the time in which the person is diagnosed but even what's happening during childhood and early adulthood can perhaps have an impact on the onset of Alzheimer's. Also, I'm an economist, I'm not a clinician, but in trying to understand Alzheimer's and other dementias, it's not just one disease in the sense that, it appears as though there are at least a handful of pathways that get you to the same place. And so we really need to spend some time and spend some resources to study this disease so that we can really develop the kinds of treatment that persons who are afflicted with it need and deserved.

**Question:** So these trials would actually determine what is effective treatment for African-Americans which may differ totally from treatment for whites or white males or anything like that for the treatment of Alzheimer's and other forms of dementias, is that correct?

**Dr. Darrell Gaskin:** That is quite possible, quite possible. If patterns for this condition hold as for other conditions, yes, that's quite possible.

**Question:** Okay.

**George Vradenburg:** Thank you very much Mr. Lowe and I want to thank again Dr. Darrell Gaskin for joining us today and for highlighting this important topic and to our own Stephanie Monroe for sharing a little more about the AfricanAmericanNetworkAgainstAlzheimer's. We're also grateful to the Zickler Family Foundation for sponsoring this call. And thank you all for participating in this Alzheimer's Talks.

In about a week, we will have a copy of the recording and a transcript on the [Alzheimer's Talks webpage](#) for you to share with your friends. It turns out that more people actually read the

transcript online than participate in these calls. So it's widely circulated and I think the information is a multiplier of the people who are able to be on the call today.

So I hope you'll sign up for our next Alzheimer's Talk teleconference, which will be on Monday, March 31st at 1:00 PM Eastern. Where we actually going to be discussing exactly what drugs and treatments for Alzheimer's are currently in the drug pipeline. Some near the end of that pipeline and, in the next couple of years will report out and some earlier in the pipeline but we will have an expert analyze all of the drugs in the Alzheimer's pipeline.

As always, please stay on the line if you would like to leave us a message with a question or a comment. So when we leave this call, you could stay on the line and leave a message and comment for us. We definitely thank you for being with us today and have a good rest of the day. Thank you all.