

Alzheimer's Talks September 8, 2017

Note: This transcript has been edited for content and clarity

Welcome to [Alzheimer's Talks](#), a free monthly teleconference presented by [UsAgainstAlzheimer's](#). I'm Jason Resendez, and I direct the [LatinosAgainstAlzheimer's network](#) and coalition. We're really grateful to you for joining us today to hear about the importance of clinical trials and especially to better understand the motivations and barriers of Alzheimer's research participation among diverse communities.

This call is in collaboration with the [Alzheimer's & Dementia Disparities Engagement Network](#) (ADDEN), which is a program that is partially funded through a [Patient-Centered Outcomes Research Institute](#) (PCORI) Eugene Washington Engagement Award. We're really excited to be able to bring together, through ADDEN, researchers, caregivers, individuals living with Alzheimer's dementia, community leaders, direct service providers, to share information and identify opportunities to collaborate around research, Alzheimer's related programming, and policy as well.

If you have any questions during the call, please press *3 on your phone. By pressing *3, you will be placed into the question queue. Please have your question ready to share briefly with a member of our staff, or if you are listening to us online, you can type your question into the box. We will get to as many questions as possible.

Please note that Dr. Byrd, who will be leading our call today, like all our guests, is not able to answer any personal medical questions on this call. With that, I will introduce [Dr. Goldie Byrd](#), who will speak a little about her work and then introduce two clinical trial volunteers who will share their experiences.

Dr. Byrd is Director of the Center for Outreach in Alzheimer's Aging and Community Health at North Carolina A&T State University. She is the former Chair of Biology, the Nathan F. Simms Endowed Distinguished Professor of Biology, and the Dean for the College of Arts and Sciences at North Carolina A&T State University. Dr. Byrd conducts research in the genetics of Alzheimer's disease in African Americans, and she is a Founding Member of the [African American Network of UsAgainstAlzheimer's](#). She was a member of the team that published the largest study of Alzheimer's disease among African Americans and she co-chaired the task force for a statewide strategic plan in North Carolina on Alzheimer's and related dementias. Dr. Byrd's community-anchored approach to Alzheimer's research has been profiled in [The Washington Post](#) and other leading media outlets.

We also are proud to call Dr. Byrd the project lead of our [Alzheimer's and Dementia Disparities Engagement Network](#) and we are excited to have her. Thanks so much for joining us, Dr. Byrd. And with that, I'll turn it over to you.

Dr. Byrd: Jason, thank you so much and thank you to everyone who has joined us this afternoon. Again, I'm Goldie Byrd and I am interim director of our Center for Outreach in Alzheimer's Aging and Community Health at North Carolina A&T State University here in Greensboro, North Carolina. Our work here covers quite a few things; we are a part of a national team that looks at Alzheimer's disease genetics and my work began by looking at Alzheimer's disease genetics in African Americans. As you all know, African Americans have Alzheimer's Disease twice more than whites and so it was a very interesting project from day one, given how little we knew about African Americans and genetics, with Alzheimer's.

But when we began to do this work, we realized that we needed to do quite a bit of community engagement work in order to sustain our work and to extend trust in the African American community. Historically, African Americans have been underrepresented in studies and clinical trials as well as many in our Hispanic population and we decided that we needed to do broad community based work in this community to establish the trust that we needed in order to be able to go in and get samples of blood, to extract DNA, and to get other kinds of research done in African American communities. This is a very sacred thing for our research team. So we've done an enormous amount of work in terms of asking the community what it would take for them to participate in the studies, what are the barriers associated, what would it take, quite frankly. And we did this work on the front end, which made it really nice, because we began to . . . simply asking the questions around trust and around getting the community involved was really important and just making a presence in the African American community.

And so we're here in North Carolina and our center is very well known for engaging the community in answering questions for us. We do quite a bit of community based participatory research and we're constantly asking the community what they would like for us to study, what is primary on their list of topics to be studied, what we're doing wrong, and what they need from us. Often what they need, we found, is understanding. And so we've done quite a bit of work around literacy and really we're finding out that there's still a lot of work that needs to be done on the literacy side, and reduce the stigma in not only the African American community but also other underrepresented communities or other underrepresented groups. And so, it's been our pleasure to establish the level of trust so that we can come back to this same community and do all kinds of research studies and ask all kinds of questions, and they do provide a lot of input in terms of what the community is feeling, around Alzheimer's disease, also, around how to get involved in studies, how to get involved in advocacy work, and so it's been great to be a part of a team of people and teams across North Carolina and across the nation, folks who are interested in making sure that underrepresented groups are included in studies and clinical trials. And

so that's still a part of the work that we do and a part of what we're doing with our PCORI award. So it's really very important for us to make sure that we're listening to folks who are like our guests today, to understand how they're feeling about participation in research and clinical trials, and they help us to understand what researchers should be thinking about, with regard to getting questions answered and filling gaps, filling knowledge gaps around Alzheimer's disease.

It is still a huge stigma related disease and we simply need to do a much better job in making sure that we're removing the barriers around stigma and that we're including family members and centers of help so that families are not suffering disproportionately with a disease like Alzheimer's. It is a family disease and we want to make sure that care providers are not burning out too soon, and so we do quite a bit of work with that as well.

So at our center, we have two locations here on the campus of North Carolina A&T, and we have a number of outreach persons as well as persons who are engaged in bench research, we host all kinds of programs and projects to bring the community to the center and then we go out to the community to engage. We of course do some very basic things, such as support groups and lunch-and-learns and workshops and galas. We engage the entire university; we are the largest historically black university, and so we engage many departments across our campus to send messages to the community and to create opportunities to bring the community to us. As an example, we host art exhibits, we host galas, we use our communications department, so we typically work through departments and units across the campus to make sure that we're messaging appropriately to communities and particularly underrepresented communities.

So, we are excited, we're still working with our collaborators at University of Miami and Case Western and Columbia Universities on our Alzheimer's disease sequencing project. and also the Alzheimer's disease genetics consortium, which is funded by the National Institute on Aging, and we're really excited about the progress we're making there, trying to understand genetic susceptibility in Alzheimer's in underrepresented groups, and in my case, particularly in African Americans. So we're just delighted to be a part of the progress here in North Carolina, as Jason said, we created a task force here in North Carolina, we were one of nine states that did not have a state plan for Alzheimer's disease and dementia so we were able to accomplish that with the Institute of Medicine here in North Carolina, and we're delighted that we are getting some funding from the state of North Carolina to create an Alzheimer's and dementia registry. So, that's a lot of progress for our state. I'm sure everybody on the call has heard about our good state in particular interviews in recent years. But this is a good thing that our state is doing and we're really excited about the energy and support that we're getting from the state of North Carolina.

I'm going to stop there and get busy with our guests today. We have two very very exciting and important guests:

Daisy Duarte is currently taking care of her mother who has Alzheimer's Disease, and Daisy is one of the persons who is also participating in a very important study, the [Dominantly Inherited Alzheimer Network \(DIAN\) study](#) at the Washington University in St. Louis. You might have heard about Daisy, because she was featured in the PBS documentary, [Alzheimer's: Every Minute Counts](#). So she's also a celebrity. And we believe that all of our care providers are celebrities. They don't get enough credit for the great work that they do. So I'm going to let Daisy say a word, and then I'm going to introduce Valerie Smith. Daisy, we're very happy to have you on board today.

Daisy: Thank you for having me. I'm Daisy Duarte. I'm a full-time caregiver to my mom; I've been a caregiver for seven years. My mom got diagnosed at the age of fifty-five, and now she's currently sixty-two. It's not an easy job but when you love someone unconditionally you do whatever you can, you know, to care for them and that's what I'm doing. I won't regret it in the long run. I'm also a clinical trial participant and I've been in clinical trials for four years now, and I hope that this clinical trial that I'm in is the one that finds a cure, or at least regresses the disease ten to fifteen years, that's what I'm hoping for. That's about it.

Dr. Byrd: Daisy, thank you so much for being here, and thank you for sharing with us. The work that you do is so magnificent and many of us have heard of you and met you and so we're just delighted that you are on board today.

I also want to introduce Valerie Smith. Valerie participates in the Gene, Exercise, and Memory Study (GEMS) and she is a study partner for her husband in a sub-study to GEMS. So we want you to say a word or two, Valerie, and then we'll begin our question and answer session.

Valerie: Good evening, everyone. I am happy to be part of this presentation. My husband and I were walking to the hospital one day and I saw this sign that said 'Memory Test' and it was free, so I said, "Well, let's go and get our memories checked," and sure enough, he had lost twenty-five percent of his short term memory. So at that point, he was asked to participate in a study, and I was his study partner. After that experience, I said, "Ooh, maybe I should be part of this clinical trial too." And sure enough, I was able to become part of the GEMS study which was an exercise program that was wonderful. And all I can say at this point is, I started out with a shrunken brain and now I have a full brain.

Dr. Byrd: Well, that's great. Daisy and Valerie, thank you so much. Could you just give us an idea of what it takes for you to participate in your studies? Just briefly, tell us what you have to do.

Daisy: The study I'm in is, I get a shot, it's an electric needle and it pumps the medication for five minutes in my abdomen. They just take my blood, my blood pressure, and temperature, for an hour after they insert the medication, and then, I'm done. And it's once a month; a nurse comes out to the house, and does that for me. And then once a year, I

travel to St. Louis and I get MRIs, tau scans, all the memory cognitive testing, all that stuff. That's once a year. And then every six months, somebody from Philadelphia comes out to my house, and they do another cognitive testing to see how I'm doing.

Dr. Byrd: Thank you. Valerie?

Valerie: My experiences started with the memory test. And I am a little leery about needles and being poked and prodded. I don't mind blood being taken, but after that, I get kind of uneasy. Fortunately, I didn't have to go through any of that, except to have my blood drawn, maybe three times during the study. I exercised three times a week, on a treadmill, and my blood pressure and my breathing rate were monitored before and after each session. The treadmill speed was increased each time I went. So by the time I finished, I was probably walking maybe a mile and a half to two miles at a pretty good clip. And I felt like a million bucks when I finished.

Dr. Byrd: Wonderful! Wonderful. Thank you both so much for sharing with us. I just wanted to share with the audience the kinds of things that you do, and of course each study is different, but these are so very important and it's important for everyone to be a part of research and clinical trials so that we reduce generalization and we have much healthier society.

So Valerie and Daisy, would you share with us, what was behind your decision to sign up for the study? I heard a little bit, but could you share just a little bit more? We of course know that you both have vested interests in this disease because of your loved ones, but why did you actually decide to go ahead and do this, given everything that you had to do, and the work that you're doing on a constant basis. Surely you, as many caregivers, you're tired, you have all kinds of things going on. What was behind your decision to participate?

Valerie: For me, the reason I decided to join the study was, most of the literature that I read about African Americans was after they had died. And so there wasn't any current knowledge about individuals who were still alive and breathing. And for me that was a big portion, to see if genetics, diabetes, thyroid, a whole bunch of other diseases that people don't know a whole lot about played a contributing factor in developing Alzheimer's.

Dr. Byrd: So you were really interested in figuring out what was going on.

Valerie: Yes.

Dr. Byrd: And wanted to contribute.

Valerie: Yes.

Dr. Byrd: And Daisy?

Daisy: My reason for joining a clinical trial was seventy-five percent of my family has been diagnosed or passed away with Alzheimer's. And I wasn't going to be a statistic. I wanted to fight, to find a cure for this before my nieces and nephew got older and they have a possibility, they have a 50-50 chance of getting it themselves.

Dr. Byrd: Interesting. And so, what would each of you tell someone, who is considering participating. What advice would you give?

Daisy: My advice to them would be, why not do it? If there's someone in your family that you love dying from this disease, why not get involved in a clinical trial, just because a clinical trial works for an African American, doesn't mean it's going to work for a Latino or it's going to work for a Caucasian. So we all need to get involved, whether it be Latino, African American, Caucasian, we all need to get involved because of that reason.

Dr. Byrd: Absolutely.

Valerie: For me, it doesn't cost you anything except time. I work every day, but I managed to get into the hospital and be on that treadmill three times a week for six months. And it was a very rewarding experience. I learned a whole lot and not just about what my body was capable of doing but also about the nutrition factor. Your diet plays an important role in these conditions that you develop.

Dr. Byrd: Absolutely. And you're feeling much better, Valerie, because of the exercise and the nutrition, so you have an immediate benefit, is what I'm hearing, in your situation.

Valerie: Exactly.

Dr. Byrd: What about researchers? And there are many on the call today, sometimes we need to hear from people like you who are or who have a desire to participate. Is there anything that you would tell us? Any advice you would give us with regard to clinical research and recruiting people like you in studies?

Daisy: I personally think that where we need to start is with the way that doctors diagnose the patient, with doctors in general. Because my mom got misdiagnosed, that's how I fell into the Alzheimer's. My mom got diagnosed with TJD, and then it came up that she had Alzheimer's, and then from the doctor that was seeing my mom, he's the one that introduced me to the DIAN study to see if my mom could join it, but my mom's too far along so she couldn't, so then I said, can I be in it? He said, "Your mom has the genetic mutation, you definitely could qualify." And that's when I joined it. So, it's like a domino effect. It starts with the doctor and it goes to the researcher involved in research, to get more people involved into research, it starts with the doctor diagnosing the situation.

Valerie: I agree with what Daisy is saying, because you won't know. For me, an ounce of prevention is worth a pound of cure. So, if you're going to the doctor, and you are

misdiagnosed, there's always a second opinion and you can do research on your own. The researchers, I think, should be commended for their dedication and commitment to identifying the genes that affect people of color, with Alzheimer's. My mom, who is ninety-two, has just developed dementia in the last three years, so of course that's another age group that interests me and to see what's going to happen. So far, it has not progressed to a point where she is incapacitated. She still moves and can get around, but she has caregivers. That is an important piece to the research piece.

Dr. Byrd: Could you be a little bit more specific, Valerie? You said she has caregivers and that's important to the research piece. How? What do you mean by that?

Valerie: Because they're there to supervise her daily activities. They are individuals who dispense medicines, they make sure she gets to all of her doctors' appointments, they are caregivers, I guess that's what you'd call them. And for researchers, I think that: keep doing what you're doing. I just think that awareness is not a priority in the African American community even though awareness about this disease has become more prevalent. I really find it scary. So far, in my family, no one has been actually diagnosed even though dementia is a form of Alzheimer's, it's probably the beginning stages, but I know my peers have parents who have passed on because of it, and I think if we had the knowledge and the medicines to either slow down the process or identify it earlier, then we would be much better off.

Dr. Byrd: Absolutely. So, it's interesting to hear you both talk about participation, and you also, Valerie, talked about another topic that hopefully we'll have some discussion about at another time which is about having help with the caring side of things. But with regard to clinical trials and research studies, many of the studies have difficulty recruiting diverse groups such as African Americans or Hispanics, African Americans or Latino participants. Talk to us about any recommendations that you would have. What do you think researchers need to know to get to know these communities better, and to be more successful in recruiting them into studies and trials? What are your thoughts?

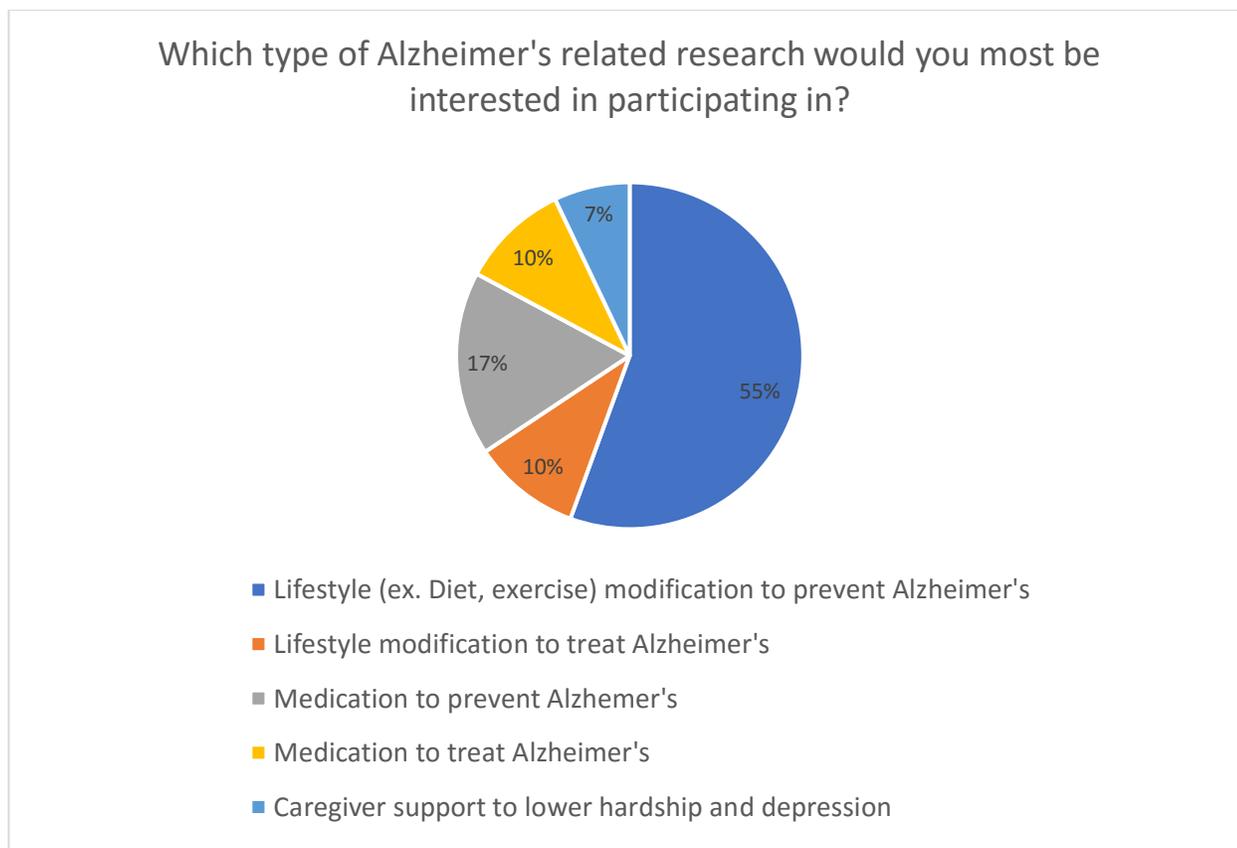
Valerie: I think knowing your family history and many African Americans do not, or they only know a piece of it. Diet. Environmental concerns. Maybe even some monetary incentives to entice the African American population to increase their participation.

Jason Resendez: Along those lines, this is Jason, we're going to do a poll question related to the conversation. So I'm going to ask and provide you instructions and you're going to use your phone to participate or if you're online you should see the option to participate in the poll. So the question is: Which type of Alzheimer's related research would you most be interested in participating in?

Press 1 for lifestyle (for example, diet and exercise) modification to prevent Alzheimer's.
Press 2 for lifestyle modification to treat Alzheimer's.
Press 3 for medication to prevent Alzheimer's.

Press 4 for medication to treat Alzheimer's.
Press 5 for caregiver support to lower hardship and depression.

I'll tell you as results come in. It looks like the most popular is lifestyle, which is really interesting as we gather and have these conversations about different ways to engage communities. So really, thank you for that participation.



We also had a question. Valerie, can you tell us again what the GEMS study was?

Valerie: GEMS study was an exercise program, where I had the opportunity to take the memory test, have some blood work drawn, go to nutritional consultations, and walk on a treadmill three times a week for six months.

Jason Resendez: And that was called the Gene, Exercise, and Memory Study, is that correct?

Valerie: Yes.

Jason Resendez: Great. And with that, I'll turn it back to you, Dr. Byrd.

Dr. Byrd: OK, great, and that's really interesting information for us to have. We all know that lifestyle and behavior modifications are so important in Alzheimer's as well as health in general so thank you all for your responses.

So I wanted to get your ideas, Daisy. We heard from Valerie, but I wanted to get your ideas around the inclusion of diverse participants. Do you have any recommendations for researchers and clinicians? What should we be thinking about? What should we be doing?

Daisy: She actually took them right out of my mouth when she said incentives and when she said get more—we're talking about Alzheimer's and I'm forgetting myself over here—

Dr. Byrd: It's okay. We can always come back to you with that, so no worries. One of the things that many researchers do is connect with communities. So do you feel that there's a role for organizations that serve underrepresented communities such as Latinos and African Americans; do you feel that there's a role for organizations in those communities to raise awareness about Alzheimer's research? And if so, what kind of things would you recommend?

Valerie: Yes, I do. I think exposure at an earlier age is important. When kids are in school and studying science, they need to know about the brain. Even though they do learn the different parts of the brain, I'm not sure that everybody is truly aware of how the brain functions. I think music is another way to engage more participation in this study. PBS Kids! I'm sure this is a podcast so that, that's available, but it's mostly for adults. I think if you expose younger people and school aged children to this particular condition, you might increase your participation in clinical research trials.

Daisy: I agree.

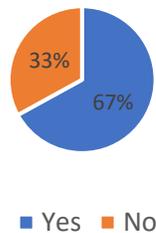
Jason Resendez: Related to that, we have one more poll question. I think these poll questions are pretty fun and helpful. The second question is: Would the inclusion of culture-based activities into Alzheimer's research opportunities and projects make them more appealing to you (for example, salsa dancing, music like Valerie was talking about, the incorporation of traditional foods)? Would these components make research more interesting to you?

Press 1 for Yes

Press 2 for No

We're seeing some results come in, and overwhelmingly people think that Yes, if cultural components were integrated into research, they'd be very appealing.

Would the inclusion of culture-based activities into Alzheimer's research opportunities make them more appealing to you? (e.x. salsa dancing, music, traditional foods)?



And with that, I'll turn it back over to you, Dr. Byrd.

Dr. Byrd: Thank you, Jason. So, we're hearing Yes for the most part. Daisy, what about you? What do you think are some roles, some things that organizations and communities can do to raise awareness about Alzheimer's?

Daisy: I believe if you're in the university, it depends on the town you're in too. If you're in a college town, the fraternities could join in. Somebody from an Alzheimer's association could go talk to them or just any organization that has to do with Alzheimer's, let them know what Alzheimer's does to the brain and they could get more involved. I'm sure they have grandparents or family members that have this disease already. There's businesses, a lot of businesses out here that, they're human just like us. The owners have family members that have Alzheimer's. They could lend a monthly or yearly dinner for Alzheimer's, you know. There's different things you can do, the more I get involved in research and everything I do advocating, you could always find a way to do something to find funding for research, or to get involved in research.

Dr. Byrd: I'm hearing that both of you feel that local organizations, local opportunities in your local community to raise awareness, to share about Alzheimer's, is something that's really really needed.

Valerie: Yes.

Daisy: Yes, definitely.

Dr. Byrd: When it comes to Alzheimer's research, what areas do you think are most important to focus on, and particularly when it comes to communities of color? For an example, which would you select: prevention, or treatment, public awareness—I just heard that that was very important—clinical trial recruitment, other areas? Would you share with us some areas of Alzheimer's research that you feel are really very important to focus on?

Valerie: I think prevention and public awareness. Also, medical terminology is sometimes scary for people, so if vocabulary could be scaffolded or differentiated, so that people are not so confused about the medical terms. I am blessed to be able to understand most everything but not all of everything, so sometimes I have to have a dictionary with me, a medical one at that, to understand the results of all the reports. So I think the public awareness and prevention, and then, I think if that happens, your participation in clinical trials will increase.

Dr. Byrd: So what I'm hearing, Valerie, is that the people who have the potential to participate really need to understand what's going on.

Valerie: Exactly.

Dr. Byrd: And then the language needs to be at a level that they can comprehend what's happening.

Valerie: Yes.

Dr. Byrd: For clinical trials. What about you, Daisy?

Daisy: I would say early prevention would be my first one. Early prevention just because if you detect it early, if you get on the ball early, it's easier than waiting for second or third stages, so I say early prevention.

Dr. Byrd: That's great. Jason, did you have another question that you wanted to ask, to poll?

Jason Resendez: Sure. We have a question from the audience. We'll start to transition to that while we load up our final poll. This is a question for Dr. Byrd from Larissa, from Florida. What are current trials for mild or moderate Alzheimer's disease, currently available trials?

Dr. Byrd: There are trials; I don't want to name specific ones here, but I'm going to refer you to the [Alzheimer's Association's Trial Match](#). I'll tell you what I'm going to, give me a few minutes, and I'm going to try to pull some up and get back to you. Thank you so much for asking that question. That is exactly what we want you to do, and I'm going to direct you probably through Jason to a couple of websites, for you to use.

Jason Resendez: Great. We'll be sure to get those circulated. Now we have our final poll uploaded. This is in partnership with our What Matters Most A-List partnership; if you've not heard of A-List, we encourage you to go to alist4research.org and you'll learn more about how you can participate in research online helping to guide the research process through your interests and preferences.

Question number three: Having learned about or seen the impact of Alzheimer's on family and friends, what one thing concerns you the most about getting the disease?

Press 1 if it's that your "senior moments" are early signs of the disease

Press 2 if the potential loss of dignity and independence is what is most concerning to you

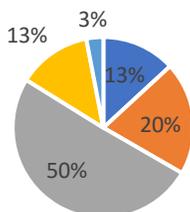
Press 3 if it's that there are no cures or treatments yet

Press 4 if it's that you will be a burden to your family

Press 5 if it's having no one to take care of you

And we're seeing early results, and overwhelmingly, so far, it's 3, that there are no treatments or cures yet.

Having learned about or seen the impact of Alzheimer's on family and friends, what one thing concerns you most about getting the disease?



- That your "senior moments" are early signs of the disease
- The potential loss of dignity and independence
- No treatments or cures yet
- That you will be a burden to your family
- Having no one to take care of you

Great. Well, thank you for participating and making this an interactive engagement. I'll throw one more question out from online. This, I think, is open to anybody, particularly the caregivers on the call. How can family caregivers encourage carees from different cultures to participate in clinical trials? Valerie, you mentioned that you were a study partner for your husband, who's participating in a trial. What is that experience like, in terms of you being a care partner and research partner?

Valerie: My job was to touch base with the researchers monthly, to see how progress was coming along. Sometimes I accompanied him to the hospital when he went for checkups, but the experience for him was phenomenal. We were in a double blind study so I don't know whether he got the medicine or the placebo. But whatever happened, it was a miracle, because when he took the final evaluation, he had regained all of his short term memory, which was a blessing, a blessing. So, all I can say is, please sign up. Don't be

afraid, if you don't like needles, there are other ways to participate, because for minority populations, there is not enough information out there for researchers to be able to find a cure. And if we all get on the bandwagon, maybe it'll happen sooner. Thank you.

Dr. Byrd: Jason, I would like to add to that. It's so important that families, as Valerie has just mentioned, talk about these things and talk about the family health history. We're actually doing a project here at our center where we're looking at the kinds of persons who serve as what we call connectors. And they connect people within the families, they're the persons who bring people together for dinner, or for family lunch or whatever, they're the persons who keep other people in the family aware of what's going on, and this is a great opportunity for families in diverse communities because often we do like to get together and talk about things.

One of the things we don't always like to talk about is health and for diseases such as Alzheimer's when no generation wants to see the next generation suffer with that, usually there are two or three people in the family who can serve as the family connector. We're actually looking to profile those individuals. We're doing family studies where we're looking for more than two people in the family who have Alzheimer's disease, [and when we send our information around for study or clinical trials, Jason will send the list to participants today, we'll include our study](#) because we're looking for families. And sometimes they're, as one of you said, there are multiple people in the family who are suffering with Alzheimer's disease, and so to be able to talk to family members and not only blood family members but people who say they're your family, and church members and friends, to talk about diseases like Alzheimer's and other dementias, it's really important to connect people and help them to understand the importance of participation.

If all groups are not included in the research, it just doesn't benefit everybody at the same level. So being able to communicate openly about diseases and conditions that disproportionately burden different groups is very, very important. And so I'm really excited about being able to bring a spouse or sister or parent together and being able to explain what the disease is, and the importance of participation is really critical and particularly for underrepresented groups.

Jason Resendez: I think those are great points. We have one question from Maneck and we will go live to ask that question.

Caller: Yes, hello, this is Maneck Bhujwala from Huntington Beach, California. I have a question as to whether, if you joined this clinical study, do you have to have Alzheimer's or dementia yourself, or are you just worried about these senior moments and not remembering names, etc., to be able to diagnose for that? And then, what are the current serious side effects for the drugs that are used in clinical studies? And basically do you have to be not participating in another clinical study? Like, I participate in a glaucoma eye clinical study; is there to be six months or a year before you can participate in that?

Dr. Byrd: Daisy and Valerie, would you like to take the first stab at that? And then I'll add some to it?

Valerie: Yes, I don't have Alzheimer's and I didn't have it, but I was interested in finding out if there was a gene that could let me know what was going on, and other than the time that I had to give up to walk on the treadmill, it was a wonderful experience. So I encourage you to sign up.

Dr. Byrd: And Daisy?

Daisy: I'd say, honestly, I don't have it, I have the mutation, I'm guaranteed to have it by the age of sixty-five but I currently don't have any symptoms. I'm forty-two, I have no symptoms, but I believe if someone in your family has it, get involved. I'm grateful I did, because now I know I have the mutation. I know that I'm going to have it. I could start doing things for . . . let's say I get it at the age of fifty; at least I have all my life insurance and everything on tap, and my family will know it's not me going crazy, they'll know it's the disease I have, the mutation is unraveling, so . . .

Dr. Byrd: Thank you both for that. And of course, yes, you can be in more than one study at a time, dependent upon what the study is. That's information that you would have to talk to your clinician or your researcher about and to have that kind of disclosure. With regard to side effects, that is also a question that is answered by the clinician or the researcher because it depends on what you might be getting. So each study is very distinct and each study, it just depends upon what the study is, and what the researchers are looking for. So, it goes back to what I believe Valerie was saying, just previously, about the importance of understanding more about the language around research and the language around Alzheimer's disease, or whatever the researcher is studying, so we would caution you to make sure that if you're making a decision about the research or clinical trials, that you understand fully what is going on, what will take place, how often you would need to be participating, what potential side effects could occur, and just ask as many questions as you can, because each study is different. Sometimes there's a very, very, very minimal risk, sometimes it's a little bit more risky, but those are things that your clinician or your researcher will be able to answer.

Jason Resendez: Excellent.

Dr. Byrd: As we are wrapping this up, I know our time is winding down, but I wanted to give Daisy and Valerie an opportunity to just share anything they would like, around participation in studies and particularly in studies that require your time, or a procedure. Is there anything that you would like to share with the audience?

Daisy: I would like just to tell everybody that if you're not in a clinical trial and you have a mutation or someone in your family has the disease, get involved. I mean, it doesn't matter if you're African American, Latino, Caucasian, we all need to be in clinical trials to

find a solution to this. We found it for cancer, we found it for AIDS, we found it for heart disease, we could find it for Alzheimer's, we just all need to work together and get involved in research.

Valerie: I agree with you 100 percent.

Dr. Byrd: Excellent. And so it seems that both of you had really great experiences with your research studies and this is a wonderful moment to share with the public how very important it is, and that you get benefits and you feel good, quite frankly, after participating. Jason, did you want to wrap this up?

Jason Resendez: Yes. First, thank you, Dr. Byrd, for your engagement, facilitation, all the work that you're doing, and above all thank you to Daisy and Valerie for not only your engagement in research, which is critical; as Daisy said, we've been able to advance the science in so many other disease areas and we really need to do the same in Alzheimer's and related dementias and that takes the engagement of all communities, particularly those communities who are underrepresented, so we're really thankful for your participation, but above all, for your voice and for really offering insights to help guide the research process which is critical and which is at the heart of what we're trying to do with the Alzheimer's & Dementia Disparities Engagement Network, so we're really grateful for you offering your insights and your voices. We encourage folks on the line to take this to heart and look for research opportunities, we've pointed it out, [Trial Match](#), for example. There's a great resource called [Antidote](#), which is a really nifty tool for identifying clinical trials that you qualify for in your area or in your region. So really, encourage you to investigate and look for a trial that's a good match for you, and then also to the researchers who are on the line, to think about the importance of engaging stakeholders in your communities, of engaging patients in your communities, to identify some of these issues. I think some of the ones that have come up have been around; the importance of prevention, the interests that the community has in prevention studies, in addition to the need to really start to explain research and research opportunities in a way that's easy to understand, really breaking through the medical jargon, as Valerie mentioned. So I think there's some really valuable insights here that we can all apply to our respective work. And we're really grateful for your time over the last hour. We look forward to staying engaged with you moving forward.

Valerie: Thank you.

Dr. Byrd: Thank you all very, very much

Jason Resendez: Thank you everyone on the phone or online for participating in this Alzheimer's Talks. In a couple of weeks, we will have a copy of the recording and a transcript on our website for you to share with your friends and colleagues. Please stay on the phone to leave us a message. We are particularly interested in your feedback on this call, and ideas for upcoming calls. Thank you for joining us and have a good afternoon.

