

**Alzheimer's Talks Transcript
Alzheimer's and the Arts**

with the National Endowment for the Arts, Interagency Task Force on the Arts and Human Development and special guests: Gary Glazner, Anne Basting, and Kate de Medeiros

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Note: This transcript has been edited for content and clarity

George Vradenburg: Welcome to [Alzheimer's Talks](#), a monthly teleconference series presented by [USAgainstAlzheimer's](#) where we connect you with the leaders in research and policy - and today the arts – who are working to stop or reduce the stigma of Alzheimer's.

My name is [George Vradenburg](#) and I'm Chairman and Co-Founder of USAgainstAlzheimer's, which we regard as an entrepreneurial start-up and a disruptive organization seeking to change the trajectory of Alzheimer's and seeking to change business as usual. USAgainstAlzheimer's is made up of people from all walks of life and all segments of the American society, people like you: [researchers](#), [women](#), [African-Americans](#), [Latinos](#), [caregivers](#), [CEOs](#), [clergy members](#) and everyone in between because this disease affects everyone. That's why we call ourselves USAgainstAlzheimer's. This fight is going to involve all of us defeating this disease. It's going to be a team sport.

Thank you for joining us today to hear more about how the arts, and specifically poetry and storytelling, might help those with Alzheimer's. We have a great panel today of Sunil Iyengar, Gary Glazner, Anne Basting and Kate de Medeiros and I'll introduce each of them sequentially in just a moment.

We've been very busy since last month's Alzheimer's Talks. The Energy and Commerce Committee of the United States House of Representatives released today a third draft of the much anticipated 21st Century Cures legislation. It will go through a markup tomorrow in the Subcommittee of the Energy and Commerce Committee. This bill accelerates the discoveries and development and delivery cycle of promising new treatments and getting cures to patients more quickly. It would also increase funding and create a special \$10 billion innovation fund for the National Institutes of Health. This is promising movement from Congress, especially since the bill has bipartisan support, but there's still work to do in the House and we still have to get the Senate moving in the same direction.

Recently, just in the last month, we've heard many politicians both in private meetings and publicly speak out on the importance of increased attention and funding for Alzheimer's. In the Senate, Susan Collins, Patty Murray, Roger Wicker of Mississippi, Senator Cassidy of Louisiana, Senator Bennet of Colorado, Senator Wyden of Oregon, Senator Burr of North Carolina and indeed some of the announced presidential candidates have been speaking about the issues specifically Jeb Bush and Mike Huckabee.

Hillary Clinton was the Co-Chair of the Alzheimer's Caucus when she served in the United States Senate, and I know from personal conversations that she is fully aware of the Alzheimer's issues and is committed to addressing them. And prior, maybe even teaser, presidential candidates Newt Gingrich and Jim Webb are speaking out about the issue. So this is beginning now to get real momentum in the political world, which is terrific. As we all know, Prime Minister Cameron has led this issue for the last year and a half as Prime Minister of the UK and he's recently been re-elected so that gives us a chance to continue his leadership on the global front as well.

To get the latest updates on all of this, please go to <http://www.usagainstalzheimer.org> and sign up, if you haven't done that already. You'll get an e-mail from us every week or so with specific actions that in fact are causing this political groundswell and shift on this disease. It will only take you about 10, 15 seconds to read an e-mail and another 10 or 15 seconds to act so this is not a big commitment of time. By joining the several hundred thousand people who have now joined USAgainstAlzheimer's, these numbers count. The Senate and House offices count these numbers so getting everyone involved is so important. We know we can stop this disease but we can't get there without your help. It's USAgainstAlzheimer's, so please join us.

We have almost 300 people registered for the call today from 39 states and the District of Columbia. Another 400 people couldn't join us today but asked specifically for the recap materials. We'll send everyone registered for the call today a summary as well as key links that we discuss today and the transcript and the recording.

Remember, if you have a question during the call, please press star 3 on your phone. By pressing star 3 you will be placed into the question queue. Please have your question ready to share briefly with a member of our staff. We'll try to get you live on the air as soon as possible with our panel, when we open it up for questions. Or if you're listening to us online you can type your question in the box on your screen and we'll try to get to as many questions as possible after the opening presentations.

So on to the panel. Today it's my pleasure to introduce you initially to [Sunil Iyengar](#). Sunil is the Director of the [Office of Research and Analysis](#) at [The National Endowment for the Arts](#), where he has worked for almost 9 years. He also chairs the National Endowment [Interagency Task Force on the Arts and Human Development](#). A key focus of their work has been the study of arts in relation to the health and wellbeing of older adults. He was very instrumental in putting together the panel you'll be hearing from today so thank you again Sunil for being with us today, for helping us put this panel together and most importantly for recognizing the importance of the arts for those with dementia and their caregivers. We look forward to your remarks.

Sunil Iyengar: Thank you George. It's an absolute pleasure to be on the line with you today and to proceed my colleagues in the field Gary, Anne and Kate. Welcome everyone and thank you for joining us.

The National Endowment for the Arts is an independent federal agency that strives to give Americans from all ages and backgrounds the opportunity to participate in the arts, to exercise their imaginations and develop their creative capacities. But for the purpose of this call I want to note that [Beth Bienvu](#),

Director of the [NEA's Office for Accessibility](#) and I have paid close attention to that part of our grant's portfolio and other arts projects throughout the nation that serve older Americans, especially projects or interventions that aim to improve health and wellbeing and to mitigate the symptoms of chronic diseases, such as the one we're talking about today. Indeed that's how we first became aware of the wonderful work of the Alzheimer's Poetry Project and Time Slips, two programs you'll hear about today. They're designed to help patients with dementia, including Alzheimer's, and importantly their caregivers in coping with symptoms of such diseases.

Besides monitoring these programs that incorporate the arts whether poetry and storytelling in this case or in others, music, dance, theater or the visual arts, we at the NEA have a strong research imperative. In 2011 we formed an Interagency Task Force on the Arts and Human Development, currently involving 19 entities across the federal government, to promote new research opportunities and information sharing about the arts role in attaining positive health and educational outcomes across the life span. I mention this group because two key players have been the [National Institute on Aging](#) and the [National Center for Complementary and Integrative Health](#) both at the [National Institute of Health, NIH](#). Together with other NIH components these agencies co-sponsored a public research workshop with us, held at the National Academy of Sciences a few years ago, to examine the relationship between the arts and aging. The events co-speakers such as Kate de Medeiros, whom you'll be hearing from also today, talked about research challenges and opportunities in the field. In many cases these were issues of profound importance to the Alzheimer's community. I invite you to look at the [report from the National Academy of Sciences event](#) as well as the [white paper on the Arts and Human Development](#), along with [a blog that was written by Kate on research needs pertaining to the arts and Alzheimer's](#).

Finally I want to say that as a researcher and a Research Director of the NEA what a high privilege it is to talk directly with all of you who have been touched directly by Alzheimer's in some way, either as patients, caregivers or in some other capacity. So often, maybe too often, we talk only to other researchers or policy makers or funders but I'd like to see more direct lines of communications with the patients and the other stakeholders. So I truly welcome this opportunity given to us by USAgainstAlzheimer's and George.

George, I'm the research guy. I went on your website and I noticed that USAgainstAlzheimer's has a theory of change and one of the goals in fact the organization hopes to advance is to bring dramatic improvements to the standards and systems of care for people living with Alzheimer's and those who care for them. So I would just urge everyone to think about how research is a key component of those standards and systems and understanding how the arts can complement or advance therapies for Alzheimer's patients. So thank you very much.

George Vradenburg: You should know Sunil that we and over a hundred organizations will be on Monday next sending a [letter to the secretary of HHS and to a number of other government agencies suggesting a research summit on care and services](#). And so as that evolves it very much seems in order to introduce NEA to that process. So thank you.

Our first presenter is [Gary Glazner](#). He's the Founder and Executive Director of the [Alzheimer's Poetry Project](#). His work has been featured in many places including [The Today Show](#), CNN and [NPR's weekend edition](#). Gary, thank you for joining us today. Please tell us a little bit more about your program.

Gary Glazner: Well thank you George and Sunil and I want to thank everybody who's on the call today. I want to tell you a little bit about how I started using poetry with people living with memory loss. It was 1997 and I got a small grant to give a series of workshops in an adult day health care center in northern California. There was no instruction on what to do, just to somehow use poetry. There was a man in the group, his head was down, he wasn't participating, he was seemingly unaware of his surrounding. I said the Longfellow poem "I shot an arrow into the air" and his eyes popped open and he said "it fell to earth, I knew not where". Suddenly he was with us and able to participate and I was hooked. It showed me how powerful those classic poems could be and how useful poetry could be with this community.

My experience as a caregiver began at that same time. My mother Frankie had terminal cancer, brain tumors and morphine were causing dementia behavior and my father Billy called one morning to say that my mom was very agitated and she was asking for cherry ice cream. And I knew this was a huge deal because my dad never asked for help. So I went and I got the ice cream and as I was getting the bag out of the car I saw the poetry books from the workshop and I just thought I'm going to bring them in and try them with my mom. My parents were childhood sweethearts, they became boyfriend and girlfriend at age five and six and as a child my mother had teased my father with a rhyme, "Can she bake a cherry pie, Billy Boy, Billy Boy". And it was one of the songs in the books that I had, and as I said it, my mother began to sing it and to do this little hand dance with her finger, 'can she bake a cherry pie, Billy boy Billy boy' and it was a moment of joy and playfulness. My mom passed away shortly after that and again it reinforced to me how useful the arts could be, in this case with my own mom in hospice. I was and I remain inspired to make my life's work serving people living with memory loss.

I started the Alzheimer's Poetry Project in 2003 and since that time we've done programming in 25 states and internationally, in Australia, Germany, Poland and South Korea. We currently have projects to work with the elders on the Navajo Nation in New Mexico with Tallahatchie General Hospital in the Delta in Mississippi and at Fishkill Correctional Facility in Upstate New York, which is one of the only prisons in the U.S. to have a unit for people living with memory loss.

Today what I want to do is to share a few techniques that we use with the Alzheimer's Poetry Project and hopefully will be of use to you in your work or with your loved ones. So the artistic focus of the Alzheimer's Poetry Project is on participant creativity. We build the sessions around classic well loved poems as an example in Lazarus' poem, [New Colossus](#), which celebrates the statue of liberty with the famous line, "Give me your tired, your poor. Your huddled masses yearning to breathe free." So we group the poems by theme and we reinforce the theme with props that have a texture or a fragrance. For instance, for the props of a summer theme, we might use roses so the person could feel the petals of the rose and smell the rose.

To engage people in performance we use call and response, and this is our main technique we use. So we recite a line from the poem and we coach the group or the person to echo the line. This use of

repetition builds on poetry strength as an oral art form and we find call and response throughout our culture. Almost all religious ceremonies have an element of call and response, including our marriage vows. Blues, jazz, and gospel have call and response built into their style and cheerleaders use call and response to excite at sport events. When we're babies, we start to learn language by tracking our parents' mouths sounds and imitating them and call and response can be a powerful tool to use in communicating with people living with memory loss. We also use touch therapy, we often hold the hands of the person, moving their hands lightly to reinforce the rhythm of the poem. We use funny poems and we encourage the people's humor. In creating poems, we draw inspiration from the classic poems and we generate lines of original poetry by asking the participants open-ended questions around the theme and writing down their comments. This is really similar to the method TimeSlips uses to create stories that Anne will talk about in a moment. Listening skills are crucial in creating the new poem, using the exact language of the participants instead of paraphrasing helps strengthen the task and we end the session with the performance of the newly created poem, again using the call and response technique. We found these methods can be adapted to working one on one with people in home settings.

I want to talk now just briefly about some of the research projects we're involved in. Last year, we were honored to have a scholar from the Netherlands, Aagje Swinnen, who was awarded a Fulbright scholarship to study the Alzheimer's Poetry Project for six months. I'm really excited to say that the paper that she wrote, [Healing Words: A Study of Poetry Interventions in Dementia Care](#), was published last November in *Dementia*, an internationally peer-reviewed journal. Professor Swinnen found, and I'm going to quote briefly from her paper, "it is the ongoing exchange between performer and participant who simultaneously produce and consume poetry that comfort is found not only for people with dementia but for the poet performer as well", which emphasizes a major goal of the Alzheimer's Poetry Project in that both people living with memory loss and caregivers benefit from the creative exchange. We've also recently worked with Dr. de Medeiros on a pilot project to study the Alzheimer's Poetry Project and to look at innovative ways to undertake studying dementia arts, and this has just been completed and I'll let her talk a little bit more about what the pilot project found.

So while participating in the arts will not change the course of Alzheimer's disease, I have seen people respond to poems with smiles, laughter and joy for over 10 years in hundreds and hundreds of poetry sessions. Entering the room for the poetry session you often find the people sitting alone, appearing withdrawn, and they have engaged as they perform and create poetry. It helps to reinforce their dignity as humans. So from the many programs for dementia arts including [Meet Me at MoMA](#), many museums have dementia arts programs, [Mark Morris Dance Company has Dance for Parkinson's](#), the film [Alive Inside](#), the [National Center for Creative Aging](#) and groups like New York based [Elders Share the Arts](#) to leaders like Anne Basting, with [TimeSlips storytelling](#) and her incredibly innovative groundbreaking theater projects, just to name a few, there's a movement in evidence-based creative aging that's reshaping how we view the aging process and changing how we view living with memory loss. I'm really excited to say that the National Center for Creative Aging is launching a caregiver toolkit to do arts projects and that's going to be launched next week as part of their conference and I'm proud to be part of that as well as Anne is part of that as well.

So this is my call for all the major advocacy groups for Alzheimer's disease and related dementias for the National Institute of Health, the National Endowment for the Arts, elected representatives, foundations philanthropists, to dedicate a percentage of their budget to creative aging research and programs, for doctors and gerontologists upon diagnosis to give a prescription to a local creative aging program, and our response as artists, as scientists, as people, as caregivers, and advocacy groups like USAgainstAlzheimer's will show that we value all members of our community, including those learning how to navigate memory loss. Now, today, this is what we can do to help them.

I'm going to close with the poem written by Heidi Jenkins from Charleston Middle School in Mississippi who participated in an intergenerational program, at Tallahatchie General Hospital and Heidi said this: "Shaking youthful hands with wrinkled hands, knowing that one day my hair would be as white as theirs. One day I might need young smiles with a mouth full of teeth to smile at me – an extra boost to make me smile. Shaking youthful hands with wrinkled hands is what changed my life." So I want to thank the NEA and USAgainstAlzheimer's and all the people on the call, it's been an honor to be with you today.

George Vradenburg: Well, thank you Gary. That was excellent, both informative but also inspiring so I appreciate that.

Next, we are going to hear from [Anne Basting](#). She's the Founder and Director of [TimeSlips](#) and Professor of Theater at the Peck School of the Arts. She is the author of [Forget Memory: Creating Better Lives for People with Dementia](#). Anne, we're excited to hear more about your work.

Anne Basting: Thanks so much George and I just want to give a great hear, hear to Gary. We travel in the same circles and I think we inspire each other's work and his call to action is one that I echo strongly.

I want to tell you where I am right now, which is sitting at my desk at the University having just finished grading my storytelling class. And this storytelling class is a group of mostly 18 year olds who are excited and nervous about storytelling and at the beginning of the semester the first thing I tell them is, 'raise your hand if you are human' and they all of course raise their hands, and I say 'congratulations, you are already a storyteller'. Storytelling is innate to the human species. We understand ourselves through narrative and through storytelling. We connect with each other. That's how we understand each other and share ourselves and empathize with each other. Storytelling is also how we connect across history and other generations. We keep stories alive from generation to generation, and you might all be thinking about your table at holidays and how family members who've gone by or previous generations come alive as we conjure them through storytelling at holidays with family. But this thing happens when we get memory loss, when we get the symptoms of dementia and Alzheimer's, that we start to struggle with the ability to keep a story in a linear track with rational language of what happened when, and in what order. When that happens people can start to doubt their capacity to control the story, to use that mechanism to understand who they are, how they connect to other people through story, they can see in other people's eyes that something is not right, the word isn't right, the order is right and so what can happen is, there is this gradual internalization, self-editing, cutting oneself off from storytelling. It essentially becomes a disease of isolation that they lose the capacity to understand, understand who

they are, to connect to other people, family and friends and community and also to figure out their place in human history and life beyond their immediate circle.

How can we bring that back to them? How can we bring that powerful tool of storytelling back to people who are struggling with memory loss and the symptoms of Alzheimer's? What we can do is a pretty simple shift from expecting rational language and the linear quality of those stories, to shift from the expectation of memory toward an opening and expectation of imagination.

I want to paint a little picture, like Gary did, of how I walk into a group of people with memory loss and work with them to use story in this way. If you imagine a group of people sitting in a circle and you have a big pad of paper and you have a marker and you bring in a prompt of some sort to prompt a story. That prompt can be, as Gary said in museums, a picture on a wall, it can be an object, it can be a question, it can be a theme, commonly what I'll use is an image. One of the first times I did this, I tore a picture of the Marlboro man out of the magazine and I brought it in. Instead of asking them who is this? Or tell me about the Marlboro man? I shifted expectation of memory toward opening it to imagination and I said who do you want to call this person? Where do you want to say this takes place? When do you want to say this takes place? What do you want to say is happening? And with those very few opening questions we created a 45 minute story that was about Fred Astaire who's married to Gina Autry and they live in Oklahoma and then we sang the song of Oklahoma, we went on and on and on about their family and their pet and certainly fused into that story were elements of their own story and their own lives but when it is in a framework of imagination there is no pressure. They could experiment with whatever communication tools they had. They could use sound, they could use song, they could use gesture whatever they wanted to do, they could use facial expression. And so you're opening up and seeing whatever strengths that person has left to communicate. You're encouraging them to use them and your connecting with them on those terms from where they are. So TimeSlips creates that shift. It's deceptively simple from expecting memory to inviting imagination and it is in that imagination that we can connect with people with cognitive disabilities, like dementia.

I just want to outline the core elements of that approach, and there are some similarities, Gary and I work very similarly. What we do is we start with accepting the person where they are. We invite them into creating a story with open-ended questions. We affirm all responses: words, sounds, songs, movements, all of those things I said. We echo and repeat them as though they are teaching us a new language. We want to make sure that they know that they've been heard. We retell that story and show that they are building something and making something together. And then we share that story with others in order to demonstrate their value and in turn the value of the person with dementia.

TimeSlips began way back in 1998 using that improvisational story technique and story circles in adult day, in nursing homes, in assisted living, all over the place. We've also worked in independent apartment buildings, museums as well. We've worked in many, many, many different places. We now have a website full of resources for families, for students, for volunteers and for professionals. We are now an independent non-profit, after being incubated in the University for about 10 years, with online storytelling training for individuals and organizations. We have on that website free storytelling game software that you can use to create your own story. A really important part of that is a collaborate

button. Families, especially those who are separated across miles, so rarely have something positive to do together because communication can become so tricky and they usually only bond together over crisis management of care. It's very difficult to connect in a positive way over the miles. So we created that collaborate button to invite a daughter in Utah to collaborate and create a story with someone in New York or wherever you are, you can do it internationally, to build through the imagination something together to have a new memory and a new story to share together. You can also read stories from all over the world, which is pretty inspiring as well. And then also as Gary mentioned too, we use stories to build community and use this process as a core process to integrate into programming either in the congregate care setting or in the home setting, we've also reached out to people living at home, in order to integrate and help them feel like they're building a larger project together.

It's that key component of meaningfulness that connects an individual person's identity with a group of people beyond themselves. That purpose of what am I beyond the next generation? How can I contribute and leave a legacy? So we've used that approach to build plays, to build art exhibits, to build all kinds of different large scale projects that people can feel like they're pouring their effort and their energy into and connecting with other people to do it. The imagination really gives us more than a program to add on top of our already busy lives. It gives us a way of being in relationship to each other, to open our minds and connect with other people and not correct each other. To connect instead of correct. I think is a really important phrase that re-orientates that care relationship to being one based on strength and individuality.

Our goal really is to get this approach and the other likeminded approaches, like Gary's and other folks you've heard about, to be standard practice in dementia care and that'll take all the training in advocacy that you can muster.

George Vradenburg: Thank you so very much Anne. It's quite inspiring to hear how you have taken this and the fascinating ways in which you allow persons with cognitive impairment to build their own stories or participate in the building of stories with others.

And we do have a question here online, actually it goes right to what you're talking about. Sally Dillan asked online, 'should you correct the patient who is telling the story incorrectly or allow him or her to tell it as he/she wants?' and I think you answered that we allow person to go where they go?

Anne Basting: Yeah I think Gary and I would both answer it the same way. It's really about accepting where the person is, correcting shuts down the entire process. What we're doing is inviting the person from where they are to express in whatever way they can even if the language might not make sense to you, you echo it for the internal sense of it, the emotion of it, in some way and incorporate that into the larger sense of the story.

George Vradenburg: It's fascinating. Let me make sure we get Kate in here and give her time and then open it up and have a conversation and bring in some questions.

Our final speaker today is [Kate de Medeiros](#). She's the Robert H. and Nancy J. Blayney Professor Gerontology at Miami University in Ohio. She recently published the book, [Narrative Gerontology in](#)

[Research and Practice](#). So her research has looked at various aspects of dementia to include social environment, behaviors and arts-based programs such as the Alzheimer's Poetry Project that we've heard about from Gary. Kate, thank you for being here with us today.

Dr. Kate de Medeiros: Well thank you for having me. It's really such a great honor to be part of this really exciting program. As you've mentioned, as a gerontologist I come to this topic as someone who's done really different types of research with people with dementia. Today I wanted to focus on four broad areas that I feel frame discussions about research on the participatory arts in dementia in particular.

The first one is how the person with dementia and what that person is experiencing from day to day often get framed in the context of medicalized language, and I think this is important to think about. [Doctor Steve Sabat](#) who's a cognitive psychologist from Georgetown writes a lot about this topic in the context of what he calls the Fundamental Attribution Error. What that means is that when a person gets a diagnosis then everything subsequently gets framed within that diagnosis even though the day before that diagnosis it might have been framed differently. For example, if I were to suddenly be uninterested or bored in something people might simply just say that I'm bored or uninterested. But if I had a diagnosis of something like Alzheimer's disease or Parkinson's then my boredom or my lack of interest might now be described as something like apathy or depression. If I'm antsy or fidgety without a diagnosis I might just be busy or again bored or whatever, but if I have a diagnosis then I might suddenly become agitated. I'm not in any way suggesting that these behavioral changes aren't real but rather that the meaning of these actions and the responses to these actions can end up being framed in really the medical context only, that's just part of the disease, that's what you can expect, rather than in that larger framework of the person needing something more enriching in their lives and in their days. And when you think about it, if a person's entire life world is limited to a few rooms whether that's at home or in a long-term care facility they might very easily become bored or antsy or some of the other things that can lead to then what we think about as behavioral disturbances. So my first point really is that the participatory arts have the potential to address the issue of having something worthwhile to do in a day by presenting new experiential opportunities and this is something that often gets lost when we think about dementia from just purely the medical aspect of disease and disease process.

The second point I want to make builds on this, and it's really what Anne and Gary have talked about already, and that's the importance that creativity and meaning-making play in dementia care. You know the world for people with dementia and their carers becomes increasingly smaller with time. With fewer opportunities to leave home, fewer chances to visit with people, fewer chances to have meaningful conversations that go beyond questions like, would you like some coffee? Or how did you like that program? And as both folks have mentioned and as we all know, communicating with somebody with dementia can be extremely difficult. Language abilities decline as dementia progresses and someone might be experiencing hearing loss on top of that, changes in memory and orientation can make conversations difficult. It's sometimes hard to even think about what to say to someone with dementia, conversations get awkward and then subsequently they can end up turning into just question and answer sessions instead of conversation or they just go away. And so that's where the improvisation and the novel ways of communicating that Anne and Gary mentioned really come in. Things like in Gary's

program call and response poetry where somebody repeats the portion of a poem or where they create a new poem or this group storytelling can change what's possible in a communication way but it also can increase interest, decrease boredom, stimulate thought and perhaps have an effect on those things that we call behavioral disturbances.

The third thing that I wanted to talk about was the way that we think about research and specifically research on the effectiveness of arts interventions in dementia settings and that includes what we consider to be a successful intervention. In research in general the gold standard of treatment research is the randomized control trial. That's the basic structure for doing drug research where some initial form of measurement takes place, let's say you assess memory at the start of the study, and then as the name implies study volunteers get randomly assigned to some sort of a treatment group and some to another group. If you're testing a new medication you might be assigned to either that new medication or to some traditional therapy. And then after a given period of time, you are re-tested and maybe several times, so that the researcher can determine if any of the changes that are seen might be linked to the treatment rather than just being by chance or coincidental and in some studies they might be interested in seeing how long these changes lasts. So features of these randomized control trials, they have large sample sizes because they need to be big enough to have statistically meaningful results, so hundred plus people generally usually much bigger than that, and then often the researchers are blinded to who got which treatment so that way it helps to eliminate bias. This is great with medications and it's very effective you don't have to be interested in a pill to have it be effective on you it was designed to have a chemical reaction of some sort and that's what it's purpose is. But then when you think about programs like TimeSlips or Alzheimer's Poetry Project and you think about research you think, well how do you go about testing that effectiveness? And that speaks to this big conundrum of testing and of research that we see in the participatory arts. This idea of a large sample size for one is problematic. Dementia care facilities vary in size, they're usually often 20 people or fewer, even within larger facilities, and the population is changing constantly because of illness, people moving in and out, people passing away. The nature of the intervention, so doing Gary's poetry or Anne's TimeSlips doesn't lend itself to being able to just randomize people across groups without expecting some kind of spillover, people to engage with each other. These things are done in groups, they're not done in isolation. So that's one huge challenge in this whole research realm. The second major challenge is, so what is a successful result from participating in this? What can you expect? Is it going to improve your memory? Is it going to improve wellbeing? Happiness? How are we going to measure that? Will everyone respond in the same way? What if I don't like poetry and I don't respond, does that mean it's not effective? What constitutes a dose of poetry? What counts as evidence? These are things that are really challenging and that we really, really need to think through.

Just to give you a brief example, Gary mentioned the pilot study that we did with his Poetry Project. What we did is we focused on looking at a small group of people with dementia, we spent time to see what they did in the morning, the time that we would do the intervention. And we found that they would come in, be fed, the activity person would offer them a beverage then people would generally appear to be dozing. The activity person might then read some articles from the newspaper to them, again limited often really no discernible interaction and that was kind of a day. We brought the poetry in

and found that things happened very quickly. People might start talking to each other. People who you thought were asleep really weren't, they were quite awake their eyes were just closed. And so, it was really interesting to try to capture what was happening. We couldn't just go in with the survey and make some check marks but there were many, many things and the one thing we did find was this potential for communicating with each other. This is people with dementia communicating with other people with dementia, this new social connectivity and this idea of communication. And these are really exciting things I think to look for in the future, but they're difficult.

The third challenge in this dementia research is money. Who's going to fund this type of research? There are a lot of people who are really interested and should be interested in funding cures and treatments, but in reality the designs that are going to test these arts interventions are actually quite expensive and labor-intensive and that's not the kind of money that goes towards these types of things. Samples aren't easy to get and again geographical areas sometimes are wide in order to get a significant number of people. So it's just another thing to think about when we think about, how do we measure and how can we go about looking at it?

So to sum up the takeaway messages for research and participatory art programs, just because there isn't clinical research to support that it's effective doesn't mean that it's not effective. Just because we don't have randomized control trials, doesn't mean it's not effective and in fact a lot of randomized control trials and systematic reviews that look at drug interventions, don't find that they're very effective either and they come with really horrible side effects. I don't believe that anyone's ever died from a dose of poetry, although I can't say that for certain. The other thing is that there's a lot of catch-22 when it comes to research. You need funding to measure the effectiveness but you can't get the funding because there are no existing studies on effectiveness. So this is a challenge that I know several people like myself keep running into. We need partnerships with experienced researchers and artists so that we can think collectively in how to redesign research so that it's still robust and rigorous but that it is appropriate to what we're measuring. And then finally if we are really going to make a difference in the lives of people living with dementia, I think we need to think beyond the boundaries of medicine alone and that medicalization of experience and really look at the wider potential of experience like the kind that Anne and Gary talked about and how that might affect change.

So thank you again for having me.

George Vradenburg: That was fascinating. I just got back from speaking at the convention of the Assisted Living Federation. So this is 2,600 people sitting in a very large room talking about what we ought to be doing with that industry in terms of research because in fact there are a number of reports of rather systematic maintenance and indeed some improvement in the cognitive performance of individuals in better care settings than in worse. And so the question arose, how does one systematically capture that result and how does one measure its value so that it will be paid for by the medical system? So your medicalization question really hit home. So what we are, I think, going to try to do with some technology companies is to be able to use wearable technologies and other mobile technologies to be able to track people on a continuous and passive basis to determine through time what kinds of interventions actually affect short-term or longer term health outcomes, whether quality of life, quality

of care or cost reductions in terms of hospital admissions or acute incidents or other things. So this difficulty, this challenge, of measuring care interventions, I think USAgainstAlzheimer's and the assisted living industry are going to try and get at. You're absolutely right, each of those residences is pretty small, so trying to do something across an industry is a way that we're going to try and attack that larger problem but that is not necessarily a placebo controlled analog. So I totally agree. All of you have raised fascinating questions, fascinating and interesting observations.

I just want to remind people who are on the phone, if you have a question please press star 3 and 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. Again if you're listening online, type your question in the box provided.

I'd like a comment from whoever would like to respond to this, and it may be Sunil, people are sending questions about music and how either listening to music, participating in music or otherwise engaging in some music-related activity can improve short-term or long-term feelings of wellness or health? So I'll start with Sunil and anyone else can comment on it if they wish.

Sunil Iyengar: George I'm happy to take a crack at that. We have seen studies, and I think one of the speakers maybe referred to this, studies looking at music and improving movement and gait, particularly with people with Parkinson's disease and neurodegenerative types of diseases. So that's been very promising. There are some really fascinating studies, particularly neurocognitive studies, looking at how music has been associated with memory retention throughout the lifespan particularly among over adults. So in this case we may be talking about people who are not already afflicted by dementia for example but so-called healthy adults. We find there seems to be a correlation between memory retention and auditory memory particularly in those who are practicing musicians and who practice regularly. It turns out there are some work by a woman named [Nina Kraus from Northwestern University](#) who's done some fascinating work, she was actually featured in that National Academy of Sciences, NIH, NEA workshop as one of the speakers and she showed us some really great results and she's published results looking at the link between music and listening and music playing on one hand and memory retention and particularly auditory memory in older adults.

George Vradenburg: We obviously saw with the Glen Campbell Documentary, the capacity of an individual who may even be in mild or moderate stage Alzheimer's, who may not know where he is off stage, but when he got on stage and was playing the guitar, whether it's just muscle memory or other kinds of memory, he was able to perform at a very high level. This notion of somehow your own history being a piece of your memory.

We have seen I think at least anecdotally that you mentioned the poem that connected with your mother, that in fact people from the African-American community or religious communities, who remember religious songs, or gospel singing or others that will connect to songs from the 50's or 40's, because that's the song from their childhood so finding the mechanism by which you deliver the memories that are still there in long term memory through new technology or simply deep interviewing that connect to each individual or something different about music and their own history is I think one of the great frontiers here in how to develop personalized care programs that really have plumbed the

individual's history, the relationships and other aspects of what may be in their memory and what may remind them and keep them purposeful and as you said reducing isolation.

There's a comment here online, How can arts programs and related services become better integrated into regular primary care? Because primary care is a phrase out of the medical world, but how can we get arts programs and related services more into a home-based, to people living in the community? Kate, do you want to start and we can get comments from anyone else who wishes to comment?

Dr. Kate de Medeiros: Well I think first it's educating providers about the usefulness. So again I think we get in this conundrum of I want to see the efficacy and thinking in that way, when in reality again it's not like it's going to damage anyone by participating. The arts need to be viewed as something that worthwhile and not a simple pastime. And I think that requires education in thinking beyond the prescription mentality that I think pervades the system because of reimbursements as you've mentioned. So, I think getting the word out there is definitely key. As someone mentioned, I think it was Gary, it'd be great if somebody could suggest to a family to be involved in a local arts program or to take advantage of the local museum as part of the care treatment for somebody with dementia.

Anne Basting: I think we're starting to see a groundswell of this happening. We know that the vast majority of people living with symptoms of Alzheimer's or dementia are living in community. They're not in congregate care settings and we're starting that movement to make dementia friendly communities where the places that you've been going your whole life for community and cultural simulation and arts and creativity, and the life of your community, they don't need to stop just because someone gets a diagnosis. So museums across the country are really starting to open up their education programs to working with families with memory loss. Libraries are starting to be a resource in that direction. I worked on a project of another adaptation of TimeSlips working with home-delivered meal services and large-scale volunteer organizations that go out to work with people living in their home. To figure out what is that simplest invitation to be creative where people don't say no because they spent their whole life saying, "I'm not a creative person." But it's just that little invitation to express in some way that's a little out of the ordinary, get them to kind of jump off the track of their usual conversations. We created a whole system of questions of the day that were worded poetically that people could respond to on a little card that came with a home-delivered meal or through a telephone reassurance program or with a volunteer who came to chat with them to keep them company. All of those different approaches of getting into the home in order to bring out the expression and create connection for people living alone who are starting to experience those symptoms or people who might have some support networks, and family checking on them but they're living with symptoms of dementia at home. That project was called the [Islands of Milwaukee](#), we're shifting it into being called Arts at Home but you can find that at [islandsofmilwaukee.org](#) and all the questions are there, all the radio podcasts we created out of the answers, you can see tons of stuff on there.

Gary Glazner: I would just like to say briefly in response to this is we have an event in Brooklyn called the [Memory Arts Cafe](#) and we worked with local physicians where they can direct someone who's just gotten the diagnosis to attend these monthly events and there's a number of memory cafes around the country, over 100 now. But I'd like to say for myself out of this call, I would like to take this on and try to

get physicians and gerontologists to know about this, the different creative arts projects and that they can make a prescription to join one of these groups. There is so little that they can actually offer the families and I think that that would be an important thing that comes out of our conversation today.

George Vradenburg: You know, we are developing a dementia-friendly America initiative in which where we're going to develop and work with a number of pilot communities who have taken this on in a serious way and you've now introduced the systematic effort to get arts into that and I think that's a really great idea.

We have a comment here from Cheryl Croce: I've benefited using music therapy myself, sing-alongs and other sensory interventions in reducing behaviors during sun downing periods and found it beneficial. You're striking a chord among those people who are responding online.

We have a few more questions but I think we're running out of time and I want to thank all of the panelists. Sunil thank you for helping us to put this together and the NEA for helping us to put this together. Thank you also Gary, Anne, and Kate.

Thank you everyone on the phone and I'm sorry I couldn't get to some of your questions. Although Holly for your question about options for people in rural areas participating in clinical trial a little off topic here, but that is a great challenge and some doctors that I've been talking with in clinical trial sites have been thinking about mobile clinical site participation so I just wanted to let you know that I wasn't ignoring your question.

Thank you to everyone on the phone or online for participating today. In about a week we'll have a copy of this recording and a transcript on our website for you to share with your friends.

USAgainstAlzheimer's and our network members have long recognized that arts represent a powerful medium to bring attention, focus, and light to the topic of Alzheimer's but also to bring a connectivity to those with cognitive deficits that we may not be able to reach through rational discussion. We know that arts can be a platform for change as well and so we're looking to engage arts in a variety of form as a way of reducing stigma more generally and to engaging more people more broadly in at least being open and willing to discuss the disease and how they might make the lives of those with the disease as helpful, fruitful, and respectful as we can. We are forming a new effort to galvanize artists across the globe who want to help us bring Alzheimer's out of the shadows. We are in the planning stages but we're confident that creating a clearing house as one person online said: in London there is an organization called Arts for Dementia, sort of a clearing house for bringing together artists in all of their different forms and in all of the positive ways that they can have an impact into one, I'm not going to say place but at least a virtual environment, where we can test the impact of different art therapy interventions and where we can compare and contrast with individuals different reactions to different kinds of arts experiences as a way to improve their well-being. As I say, we're in the planning stages but are confident this new initiative will give not only more voice to Alzheimer's, engage more people in the fight, but also bring a greater sense of well-being to those that are experiencing the disease and quite frankly we should mention the caregivers who themselves are going through the experience of Alzheimer's. Thanks again to the NEA for being with us today as we explore this topic and I think we'll be

back in touch Sunil about bringing together the people you deal with and the research approaches that we may be exploring here fully mindful of all the research methodological questions that you cannot automatically transport to this field and also to the obvious point that's in fact arts can't hurt.

[Our next call will be on Thursday June 25th from 3:00 to 4:00 pm Eastern](#) and will feature [Dr. Katrin Andreasson, professor of Neurology at Stanford University Medical Center](#). You may have seen some recent press about her interesting research. [She's able to reverse memory loss in mice by focusing on the microglia, also known as the immune cells in the brain](#). She'll be joining us next month to talk about her fascinating research. As always, please stay on the line if you'd like to leave a message or a question or comment, we're particularly interested in what you would like to discuss on future calls.

Thank you to the panelists. Thank you Sunil, thank you all for joining us today and have a good afternoon. Bye-bye.

Guests: Bye. Thank you.