

# UsAgainst Alzheimer's

Alzheimer's Talks  
with Lisa Genova  
October 24, 2017

**Note: This transcript has been edited for content and clarity**

**George Vradenburg:** Welcome to Alzheimer's Talks, a free monthly teleconference presented by [UsAgainstAlzheimer's](#). My name is [George Vradenburg](#), I'm Chairman and Co-founder of UsAgainstAlzheimer's, and I want to thank you all so much for joining us today to hear from Lisa Genova, the famed author and Harvard-trained neurologist.

Just a few notes up front about what's been happening here in Washington; it has been a busy several weeks. So I'm going to give you a quick update on a couple of those items although for those of you who get the emails from UsAgainstAlzheimer's, you'll get this in more detail, as well as other items, in our monthly wrap-up.

Earlier this month, we—as in, UsAgainstAlzheimer's—convened the [National Alzheimer's Summit: Uniting Communities for a Cure](#). This was a three-day summit here in D.C. where we brought together researchers, community and industry leaders, journalists, individuals living with Alzheimer's, and their care partners, and more than a dozen Congressional leaders. The first day was focused on disparities in the field, a disparities symposium, Diversifying the Race for a Cure & Care, led by leaders of our [AfricanAmericansAgainstAlzheimer's network](#) and our [LatinosAgainstAlzheimer's network](#). And as you might expect from the title, it does focus on the fact that Latinos and African Americans are more likely to get the disease; they experience a much greater percentage than their population would suggest of the financial burden and social impact of the disease. And it is a matter as to which we need to focus a good deal.

The second day of the summit was a general discussion of where we are in the pipeline for drugs to a cure, where are we with respect to regulatory and reimbursement issues from Medicare and Medicaid, and we also talked about what we might learn from other movements—the breast cancer movement and HIV/AIDS movement.

That second night, we celebrated a very large 500-person dinner in the name of my late wife, Trish Vradenburg, the [Out of the Shadows Dinner](#), and we honored two of our Congressional champions—Senator Roy Blunt of Missouri and Senator Debbie Stabenow of Michigan—as well as a person who is a caregiver for her mother, with Alzheimer's, and who herself has been diagnosed with the gene that will produce early onset Alzheimer's, Daisy Duarte.

And on the last day of the summit, we hosted a Capitol Hill advocacy day, where over eighty activists who came in from around the country spoke with over 100 House and Senate offices, so these are people who came from states all across the country, and

who went to see their Congressman or Congresswoman and their Senators to urge upon them greater focus both in resource and policy on the disease.

At the summit, [we launched our newest network](#), the seventh of our networks: [VeteransAgainstAlzheimer's](#), based upon the emerging evidence that in fact war-related trauma injuries, PTSD, TBI and blast-related injuries are significantly more likely to convert to Alzheimer's later in life. And as a consequence we worked with not only the Veterans Administration but with a number of veterans' services organizations led by the VFW, the Veterans of Foreign Wars, to mobilize veterans in the fight against Alzheimer's, to increase both the resource and focus of veterans' related research on the subject, and to increase the participation of veterans in clinical trials. As we know, the first person cured of Alzheimer's will be cured in a clinical trial.

We also [released a report](#) called [\*Hiding in Plain Sight\*](#). There are certain demographic changes that are occurring in the United States which are making our national capacity to absorb the financial and social impact of this disease more difficult: more and more seniors living alone; families who are geographically fragmented; income inequality which will be exacerbated by the financial burdens of caring for this disease. So estimates for the impact on America that have currently been made are inadequate to explain and to understand the burden that's going to happen in the United States from this disease.

Finally, there was also for the first time a care research summit at NIH to examine the status of our knowledge about how best we ought to make sure that care is adequately delivered, that the quality of life of those with the disease is addressed, that we actually identify what it is that is being done that is working, and working well, and working better, and to spread that knowledge and the implementation and scale of those practices nationally. That summit will produce recommendations to the NIH and other government agencies on funding priorities and on practice priorities. The recommendations will also be delivered to the private sector so that we can address as a nation the deep concerns of those experiencing this disease, and their care partners.

So that is just the last few weeks, and of course we're going to talk about another development of some importance on this phone call, which is the development of a potential [Alzheimer's XPRIZE](#) that might be launched next year. Lisa was a critical partner in that team that presented at the XPRIZE Foundation for an opportunity to launch an XPRIZE next year and we will talk about that.

So with that said, I am very, very pleased to be able to introduce a friend and as a fan, a star of the field, [Lisa Genova](#). Many of you are familiar her as the award-winning author of [Still Alice](#), about a Harvard professor with early-onset Alzheimer's disease. It spent fifty-nine weeks on the *New York Times* bestseller list and was made into an Academy award-winning film starring Julianne Moore. Actually Julianne Moore won the Academy Award for her role in that movie. Lisa has also written [Left Neglected](#), [Love Anthony](#), and [Inside the O'Briens](#). Her next book, [Every Note Played](#), will be released in 2018. Lisa graduated as a valedictorian, summa cum laude from Bates College with a degree

in Biopsychology, and also has a Ph.D. in Neuroscience from Harvard University.

Before Lisa's initial comments, just a reminder to all of you, if you have a question during the call, please press \*3 on your phone. By pressing \*3 you will be placed into a 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 in the box, and we will get to as many questions on the phone or online as we can during the course of this call.

Please note that Lisa, like all of our guests, is not able to answer personal medical questions on this call.

Thank you so much for joining us today, Lisa. I would love to have you discuss how it is that you got into the mind of Alice, and told her story from inside out.

**Lisa Genova:** Thank you so much, George. So, the research I did for Alice involved reading everything I could, shadowing neurologists, talking to neuropsychologists, genetic counselors, general practitioners, and then coming to know twenty-seven people living with early onset and/or early stage Alzheimer's. And I was in touch with those folks pretty much every day for the year and a half that I was writing the story. And I was trying to get at, what does it feel like to live with this. That question is the key to empathy.

What we really want while we're waiting for a cure is some way to stay connected to our loved ones who have Alzheimer's, to continue to have a meaningful relationship with them, whether it's your grandmother, your mother, your spouse, to continue to have connections. And even though they might not know who I am any more—my grandmother had Alzheimer's and she was really the seed for this book—she didn't know who I was but she could still recognize that I was someone who loved her.

So how can we stay connected? And the answer has to do with empathy. And, I had a really hard time getting to empathy with my grandmother. I had a lot of sympathy for all of us . . . but I couldn't really collapse the distance to feel with her. I could feel *for* her but not *with* her. And so in addition to doing all of that academic research, and primary research where I was rolling up my sleeves and sitting in on neuropsych testing with patients, and every day emails and phone calls with people living with this, folks like Greg O'Brien—who is on our XPRIZE team who lives with early onset Alzheimer's, and wrote a great book called *On Pluto* that anyone interested in more about this should read—also serendipitously while I was writing this book, I was training as an actress. I figured while I'm a neuroscientist writing a novel, I might as well just keep going here. I had always wanted to learn how to act. So I was enrolled in acting lessons for about nine hours a week in Boston. I was acting on stage and in independent films and, interestingly, improvisational acting teaches us a lot about how to stay connected to someone with Alzheimer's.

The number one role in improv acting is, you say "Yes, and" to everything that's offered

to you. So with improv you don't have a script, you don't know what the other person is going to say. In order to create a relationship that grows and builds and becomes something, you have to agree to the reality that the other actor offers you, and then add to it.

The example I love to use is, if I'm on stage with an actor and he says, "Hey, I've got a magic carpet, do you want to go for a ride?" my job is to say "Yes, and", to agree to what he has just offered and add to it. So I would say, "Sure, I'd love to, let me grab my bikini and let's go to Tahiti."

So now we're doing something, we're in a relationship. If I say, "No, that's not a magic carpet, that's an ordinary rug" or if I say, "No, I don't feel like it", if I negate the reality he's offered, then the scene is dead. We have no relationship.

The same is true for dealing with someone with Alzheimer's, especially in the more advanced stages. When someone you know and love has Alzheimer's, they don't have access to the same reality that we do any more, right? If you have Alzheimer's, you lose access to your most recent memories and personal history, that peels back like layers of an onion, to the younger years and earlier memories, and so people with Alzheimer's can't join us in our reality. It's our job to say "Yes, and" to them and in doing so we can create a relationship in the moment that can build and grow and become something.

Another example that I love to use, I did a healing moments workshop once that uses the rules of improv acting to understand how to stay connected to our loved ones with Alzheimer's. And we were doing this very simple exercise. The instructor asked us all to give a simple statement, something we believe to be true. At the time I said, "I have a beautiful six-month-old baby boy." To which the instructor looked at me and said, "No you don't, all your children are grown." And when it was my turn again, I said, "It's a beautiful sunny day outside," and the instructor said, "No, it's raining actually and you're not going anywhere."

So here's what I noticed. I noticed that, while I knew this was an exercise and I clearly understood the point of what we were doing, I noticed my physiology, I noticed my posture. My arms were crossed, my shoulders were up, I could feel the ingredients of adrenalin buzzing through me. I was annoyed with her and if this woman disagreed with me one more time, I was going to argue with her, is how I felt. And what was so interesting, is that we were disengaged, we were ready for argument and battle.

And then she came around again and did the same questions, and I said, "I have a six-month-old baby boy," and this time, she looked me in the eye and said, "Yes, you do, and he has your eyes." And I couldn't help but smile. And then I said, "It's a sunny, beautiful day outside," and she said, "Yes it is, would you like to go for a walk?" And you can see how, by saying, "Yes, and" invites the opportunity for a relationship. So these rules of improv are really helpful for being with people with Alzheimer's and being in the moment.

It's tricky for some folks at times, because it can feel like lying, but it's more offering emotional truth, the language doesn't so much matter. I talk to people about how, often times people will say, "Well, I don't go visit my dad, he's in assisted living, he doesn't know who I am any more, so it doesn't really matter if I show up or not, he won't remember that I was there." And I say, "Well, this is true, he might not remember what you said, and he might not know who you are any more, he might not remember that you were there, but he'll remember how you made him feel."

So in that same exercise when the instructor was annoying me, do you ever get in an argument with someone in the morning, and you're still angry later in the day, hours later? You might even forget what was said, but you still feel the anger. That emotional memory lasts. And likewise, if you have a beautiful moment with someone in the morning, you might still be riding high from that all day long.

So people with Alzheimer's might not remember the content of what you said in a minute. Their short term memory might be really that short. But the way you make them feel, the emotional exchange, can last far beyond that and that's what we're searching for, in the absence of a cure.

**George Vradenburg:** So, I have heard you speak about this before. And you also talked about the very process of acting, as one in which you were trained to be inside another character and have to be someone else. So that the very rules of acting itself empower you to think through how it is to be someone other than who you are, and to be able to speak about that, in a sense, in character. I wonder whether that itself is also another sort of intriguing example of how to get inside the character of someone you do not know.

**Lisa Genova:** Yes, absolutely. So, a lot of the rules of acting apply beautifully to writing and getting inside someone else's experience, which really is what empathy is, right? The ability to walk in someone else's shoes. So this idea that you're always telling the truth, what do people want from each other? How are people changed by what happens? It's this idea of getting around that internal editor that we all have, because we've been socialized to behave, right?

So, for any of you who've raised children, when they were toddlers, toddlers are really great at expressing raw unedited emotion, and we essentially beat it out of them. We scold them and shame them and tell them to use their words. I have three kids and my youngest is now seven so she's pretty good at this point but she can still melt down. If she wants a cookie five minutes before dinner and I say no, a toddler in particular can lie on the floor and scream. It's life and death. I WANT A COOKIE! As parents, if we're having a good day, and we don't join them and yell at them back we'll say, "Shh, stop that, use your words. You can't have it. Shh. Be quiet." And what we're doing is, the circuitry of this is, we're sending inhibitory connections from our frontal lobes, that's your thinking brain, your decision making, rational part of your brain, we're sending inhibitory connections from that to the amygdala, which is the primitive emotion center. So your primal, raw emotions—grief and rage and lust and joy —those are all there. What we do

is, we become socialized, first as toddlers and then as teenagers, when the lust piece comes in, we teach ourselves to keep our emotions tidy, small, acceptable. Don't scream when you're angry, don't cry when you're sad, don't lust after the first attractive person that walks by. We want to keep it tidy.

And while that may work for moving around in the world, it doesn't work well for acting, or writing fiction. You want to be able to get around that inhibitory connection, that voice in your head that sounds an awful lot like Mom or Dad that says, don't you do that, people will think you're crazy, or don't write that, I don't approve. And get at what it really feels like. Because Alzheimer's is not neat and tidy. There's a lot at stake with this disease for both the people who have it, and all of their loved ones.

Everyone goes through the stages of grief with this disease. At any given point in a family, if Mom has Alzheimer's and you've got Dad there and you've got three kids, Mom might be in acceptance, Dad's still in denial, the oldest is in anger, the next one's in denial, the other one's in bargaining, and then you're all trying to have a sensible conversation, but the emotions are in completely different places. So to be able to write about that, you have to be able to go to those places, and live there honestly, so acting really helped me do that.

**George Vradenburg:** Let me ask, you also spent so much time with more than twenty people with the disease. Did you find that experience, that there was heterogeneity in how people communicated and how people responded to you? Was there a fair consistency across those families or individuals?

**Lisa Genova:** There were some consistencies. I think the group was somewhat self-selected in that they had enough resilience and determination, sort of like Greg; they were willing to raise their hands and say, you know what, despite what I'm going through, I still have enough reserve and enough generosity to want to help. What can I tell you about what's going on with me? So I had a pretty positive selection of folks who were willing to chat.

But that said, I just got an email today about the spouse of a woman with Alzheimer's who just died. So some folks are still around and we're still in touch and some have since passed. The journey has a lot of ups and downs and turns and things go sideways sometimes, and so every day is today.

For example, one woman today was fine and then the next day she looked at the keyboard on her computer and she couldn't make sense of any of the letters and so she dropped out of communication for a while. They added Namenda to her cocktail in addition to Aricept and the fog cleared a bit, and the letters came back, so she rejoined us for a while.

So people go through different phases of this disease, there are plateaus and then things dip down again and you get used to the new normal and the ground moves again. So, I was witness to all of it. I was very lucky that everyone was willing to trust

me and let me in and show me their most vulnerable selves. I mean, this disease is you at your most vulnerable. People have gotten divorced in the middle of this, lost spouses in the middle of this. It's hard.

**George Vradenburg:** You mentioned your grandmother had Alzheimer's. Talk to us a bit about her, about your relationship to her, how that has affected your willingness to get involved in this fight.

**Lisa Genova:** So my grandmother, she had nine children, she was as smart as can be, she was very independent, my grandfather died back when I was seven. She swam every day at the Boys Club, she was physically fit and mentally agile, and she probably was living with Alzheimer's I would say at least five to ten years before any of us recognized it as such. So, she was diagnosed in her mid-eighties and she lived alone. The nine kids, and I'm one of the youngest grandkids of about thirty of us, we knew that she had been becoming forgetful, but like a lot of families, we assumed that this was a normal part of normal aging, and we were also in denial. No one wants to see this happen to someone you love, so we were very happy to look the other way and not pay attention to the mistakes that she was making. Likewise, my nana was not a complainer and she was very smart. So she, I think, danced around her symptoms with dementia for a while, not letting us know what was going on either. My father had taken over the checkbook and we thought well, she's getting old, this is what happens, and she was forgetting things and having a hard time with words, and again we thought, well, this is normal aging.

And then, she walked to the bowling alley in the middle of the night, insisting it was the middle of the day, calling members of her bowling team, and was really disoriented as to time and place, and this just didn't seem like a normal part of normal aging, and so, in fact, it wasn't. At that point, she was diagnosed with Alzheimer's. It was really hard on her and my whole family. My aunts became her primary caregivers, in particular my aunt Mary, she and her husband, my uncle Barry, they ended up selling their house and moving in with her, and my aunt ended up quitting her job because caring for my grandmother was an around-the-clock job and we're very lucky that my aunt was able to do this and stay home with her, which is not the case for most people.

And it was hard for me. The caregiving didn't fall on my shoulders; I was one of the youngest grandchildren. I lived nearby, I loved my grandmother, we were always close, and so I would go over to visit and I was very unnerved by her strange behavior and that she didn't know who we were any more and that she wasn't making sense and repeating herself and she was upset with herself, I think, that she couldn't understand what was going on, and I didn't really know how to stay connected to her. So all the reading I did at the time—I read the scientific literature, I read the nonfiction books like *The 36-hour Day*—and while these were helpful to an extent, they helped, they satisfied the neuroscientist in me, they helped me as a caregiver, but nothing really helped me as a granddaughter. I really lost my connection to my grandmother because of this disease and I wish I understood then what I now know. So part of what is quite rewarding for me is to be able to help people who are on that similar journey maybe go through it with a

little more grace than I did.

**George Vradenburg:** This is a question from Bob Tomashevsky in Archer, Florida. Is there any sense in knowing if one has Alzheimer's as long as there is no cure, and if so, why?

**Lisa Genova:** Yeah, there's a lot of sense in knowing. From my experience in talking with people who have been diagnosed, and these are people in their forties, fifties, sixties, and seventies, pretty much everyone says that they thought they were going crazy, or they thought they had a brain tumor, or they thought they were somehow lacking in character, they'd always been responsible and on time and always remembered things and were good at things, and suddenly they were failing at various tasks, couldn't be relied upon, and so while of course the diagnosis is devastating, in terms of, it's a fatal illness with no treatment and no cure, every single person I know who has this says there was some sense of relief in knowing, well, this isn't my fault. I have the disease that 5.5 million other Americans have, so at least I know why this is happening.

And then there are things you can do to stave off the progression of the disease. So pharmacologically, we know that while the two classes of drugs that are approved for Alzheimer's don't actually get treating the disease, they don't stop the disease from progressing—these are drugs like Aricept and Namenda—we know there as a two-year study out of Mass General that showed the people who are on both Aricept and Namenda fare significantly better than those who are just on Aricept and they do even better than people who are on nothing. And by doing better, I mean activities of daily living and quality of life, so your ability to plan, problem solve, get through your day, know how to work the coffee maker, the car if you're still driving, know how to function in conversation and again, the activities of daily living. So we know that.

Beyond what's prescribed for Alzheimer's, we know that the very low-tech things like people who are on a Mediterranean diet, so, nuts and olive oil and berries and fish, they cut their risk of developing dementia by a third.

We know that sleep is super important; there are a lot of recent studies that show that low wave deep sleep helps clear away the proteins that are involved in accelerating this disease. And a lack of sleep, in fact, contributes to the progression of this disease. So we know that sleep is important.

We know that managing stress is important. High levels of stress will contribute to memory loss. We know that exercise, aerobic exercise, has been shown to clear away amyloid beta, that's the protein that's involved in the progression of this disease, we know that aerobic exercise clears that protein away better than any pharmaceutical we've yet identified.

So exercise, sleep, diet, we know these things can help you, buy you time. It can delay the progression of the disease; tip the scale in the other direction.

And then we also know that while you have the disease, the idea of cognitive reserve, so this idea that the more you learn the more neural circuits you have available to detour any wreckage in your brain produced by this disease. So, like my grandmother who was pretty smart, even if she had Alzheimer's present in some of her circuits, she might be able to get around those and get the answer she needs to accomplish whatever she was trying to do.

So, knowing your diagnosis helps you also plan for your future financially, helps you plan emotionally. This disease, it's not easy for entire families to move through, so to not know what's going on means that you're likely not prepared for what is going to happen. So, while no one wants this to be your future, I think to know gives you some things you can do to stay mentally healthy for as long as possible and it gives you some time to emotionally, financially prepare for what lies ahead.

**George Vradenburg:** So let me shift a minute here to your experience on the XPRIZE team. I had the great honor of being part of that team with you, but I would love to have you just describe your experience. What was the outcome of this particular process and what was your own experience in going through this process?

**Lisa Genova:** Well, it was so fun getting to know you on this journey, George. So, XPRIZE. I had never heard of this thing as of April. In April, I was in Vancouver for the TED Conference, I had just given my [TED Talk](#) on ways to prevent Alzheimer's disease, and I was approached by a guy named Marcus Shingles from [XPRIZE](#) and he wanted to know if I wanted to be part of the Alzheimer's team. And I said, you've got to back up; I don't know what XPRIZE is.

So, it's really fascinating and I'm actually really happy to know that this exists in our world. XPRIZE is an organization whose goal is to crowd source solutions to huge global problems that affect all of humankind, that aren't being solved by the traditional methods of solving problems in that space. So, for Alzheimer's, ultimately we'd like a cure, we also need a way of detecting this disease early because unlike any other disease out there, we don't even know how to detect this thing until it's really basically too late. By the time you're showing symptoms of memory loss, language problems, cognitive deficit, this just means it's already been ablaze in your brain for ten to twenty years. And so that's like detecting cancer in late Stage 4 and saying, okay, now what do we do?

So we need something to detect it early, we need treatments, we need cures, we have none of those three things right now. And so, what's been going on?

Well, the traditional means of trying to solve these problems for Alzheimer's involves academic scientists, neuroscientists, who will write grants to the National Institutes of Health asking for money to do their experiments. And they write the grants, they wait, they see if they get some money, they probably get a little bit, not much, because Alzheimer's is wildly underfunded. Then they do their experiments, and these

experiments tend to be pretty safe because if they don't work, then they're not going to get another round of funding. So they make very small incremental steps, if any, in science and they also don't collaborate. A lot of folks in science, the very structure of how that works means you work alone, and these folks are up for tenure, they want the Nobel Prize, it's a lot about individual power and prestige and accomplishment.

And then there's industry, so there's companies like Pfizer and Biogen and Genentech. They have a huge enormous stake in this. They're investing, I think it costs over a billion dollars and twelve years to get a drug through clinical trials. And because of this, in part, they can only afford to go after one drug after a time, so they put all their eggs in one basket. And again, they're not collaborating with anyone. So Biogen doesn't know what Pfizer's doing or in fact what they've already done, so all the drugs that have failed in clinical trial, companies don't know what the details of that involve, so they might actually be developing a drug that has already failed in someone else's clinical trial.

So the whole thing is a bit of a mess, the way we're going about this, and while I do think the scientists involved are brilliant and they are some of my dearest friends and they are working their tails off day and night, devoting their lives to this, I just think that the structure that they find themselves in, like if I were still doing neuroscience research, there are only so many ways that I can try and tackle Alzheimer's and the structure doesn't really work.

It really needs to be overhauled. It needs to involve collaboration. Let's get all those brilliant minds thinking together and let's not just involve the neuroscientists but who else might be able to look at this problem and see it with a perspective and a different lens and a different way of being trained that might be able to see a solution.

So, XPRIZE: we put together a proposal saying, okay, anyone in the world who could come up with a way to detect the presence of Alzheimer's before the pathophysiology or the symptoms occur, and that biomarker or biotarget or measurement also informs as to how we might intervene and stop this disease, whoever can do that is going to win the cash prize. So it's like American Idol for Alzheimer's.

But our team competed against some other worthy proposals for clean air, cybersecurity, voting, and zero waste mining. And these are all very worthy and needed projects. And yet our team, we—I don't even know how to word this, George—we came out on top. So the summit that we attended a few weeks ago, the people attending were philanthropists and tech guys and creative folks and influencers in the world who looked at all these proposals and evaluated them according to criteria that would mean that they had a likelihood of being successful. And we blew it out of the water. We got the highest marks by far.

Which tells us that the world is ready for a solution to Alzheimer's. We need to put an end to this disease. This disease is a monster. And we've got 5.5 million Americans now, and almost fifty million people worldwide with this disease and that's going to jump to 150 million in the blink of any eye.

We've got everybody aging; 100 years ago we lived to forty-five years, and now we can expect to live—at birth, it's seventy-eight, and by the time you're my age, it's like eighty-five or ninety, so that's awesome, but not if you've got Alzheimer's. One in three people who are eighty-five have Alzheimer's now. The situation is really untenable and I think that that everyone in the XPRIZE summit realized we need a solution to this and the way we're going about it right now, isn't going to fix it, not in the near future.

So all those brilliant scientists, while they're dedicating their lives to Alzheimer's research, they're not being supported in their efforts in the proper way. So, what XPRIZE aims to do is, anyone in the world who wants to solve this, if you're a data hacker, a physicist, an imaging specialist—you know, imaging specialists made a huge contribution to the solutions for cardiovascular disease, so for any of you out there who are at risk for heart disease, you may have had a camera threaded through an artery up through our leg into the vessels feeding your heart and they may have put a stent in there to open up one of those vessels, and that technology wasn't invented by cardiologists, it was invented by engineers and imaging specialists.

So, what we're hoping to do now that we've made it past this first hurdle, and we made it through this gate, our team now gets to put together the structure and framework and criteria to launch this competition, hopefully some time next year, to the world and say, hey, anyone out there, can you solve this and crack this code for us and get us a diagnosis and intervention for Alzheimer's.

**George Vradenburg:** Great. There's a question online about what the website address is for XPRIZE. It is [www.xprize.org](http://www.xprize.org) for further information. Go there and you'll get to know the XPRIZE Foundation a bit.

**Lisa Genova:** And I think our team's closing speech by Ken Dychtwald is up on that site and if you go to Visioneers or Summit you'll find an [Alzheimer's team](#). If you have time, it's worth listening to that closing speech; it was phenomenal. It gave a really great sense of what we've been up to, and what we're up against.

**George Vradenburg:** And you will end up standing up and applauding and cheering once you've heard that speech even if you're at home and alone.

Guy Bisschops from Belgium sent in this question, and I'm fascinated by the wisdom of this question: If we can't make an accurate diagnosis of Alzheimer's and its subtypes, how can we find a treatment? Does that not sound like our prize?

**Lisa Genova:** Exactly what we've been up to, so thank you for that question, you totally could have been on our XPRIZE team. Of course, all the pharma companies and even the neuroscientists, everybody wants the sexy solutions to the whole shebang, let's cure Alzheimer's, but how do you hit the target when you don't have a target? How do you cure it if you don't know what you're going after?

So, we backed it up and said, well, we need to be able to detect who might get Alzheimer's so that we can prevent it or treat it, so how do we detect it? And not enough people are concerned with this, and again, this is the fact that, if you wait until someone fails a mini-mental state exam or if you wait until someone can't subtract seven by 100 a few times, if you wait until the symptoms are there, then this molecular war that's going on in your brain that resulted in that behavioral cognitive memory problem, that's been going on for ten to twenty years, the brain is ablaze with Alzheimer's and it's a really complicated problem at that point. So we need to detect this disease really early if we're going to have a hope of solving it, and it's like anything else, like heart disease, you don't wait until after you've had a heart attack and then say, okay, now how might we approach keeping you alive. Cancer you don't say, well, at stage 4, come talk to us and then we'll see what we can do for you. So with Alzheimer's, it's the same thing. We really have to figure this out early. There are different types of Alzheimer's in terms of whether it's 100% genetic, how many genes contribute to your Alzheimer's, there are other kinds of dementias that are cousins of this disease, but they sort of funnel into the same disease, we don't exactly know yet, this is information that is part of this disease, is knowing what the disease is at the beginning.

So we can't come in and solve the disease; if the disease is one to ten, it's much harder to come in at ten than at one. So our XPRIZE team has proposed, you've got to come in at the beginning, so let's figure out what the beginning is, and then let's kill it there.

**George Vradenburg:** So, we've got a call here from Bob Arnoff from Cleveland, Ohio. Bob, go ahead and ask your question of Lisa.

**Caller:** Yes, Lisa, I'm a big fan of you and your book, so my question is, you mentioned that the XPRIZE is dealing first with detecting the consideration of Alzheimer's, and if I had a team of researchers that were working on prevention and optimally a cure for Alzheimer's, are they ruled out of the XPRIZE if they find a prevention and a cure but not a detection?

**Lisa Genova:** Well, if you find a cure then, yeah, we don't need the XPRIZE. Well, I'll tell you the truth; that kind of depends on what kind of cure it is. We talked about this too, right?

So say you're a team of scientists and you're working on a treatment for Alzheimer's, and you find something that stops the progression, and there are millions of people out there who could benefit from this treatment. So while there are those folks who have already been diagnosed who might benefit from your treatment depending on if their treatment works, if they're not too far along in the disease, what about the millions of others who don't get a diagnosis?

It's a huge problem in this disease, that, when we say there are 5.5 million Americans with Alzheimer's, the number of people who actually have this is likely millions more, because most people aren't diagnosed with this disease or they aren't diagnosed for years and years after the initial stages of it. Like my grandmother who was probably

walking around with Alzheimer's for ten years before we actually got her proper diagnosis.

So, if you come up with a treatment that's fantastic, we also need to identify who gets it. If my grandmother didn't have a diagnosis, she's not going to go look for a treatment. And likewise, I guess that if treatments were available, it's what we see with autism now, there's so many more autism diagnoses out there and part of that is because we have resources for them that we didn't used to have. And so, people are going in and being counted.

So would you be eligible for the XPRIZE? There's going to be very specific criteria for our XPRIZE, so if you're working on something else for Alzheimer's and it doesn't have to do with finding something that predicts the occurrence of Alzheimer's, then I would imagine that you don't qualify for this particular prize. If you find a treatment for Alzheimer's, your pot of gold will likely come from somewhere else.

**George Vradenburg:** The XPRIZE in this space will be launched in 2018, with, as Lisa said, very specific criteria for what we're looking for, and as she noted, since people have the pathology of this disease fifteen to twenty years before symptoms appear, the opportunity to intervene during that period when you appear to be cognitively normal but you have the pathology of the disease in you, says if we can identify people at that stage, and identify them in a manner that you could use that means of identification to stop the progression of the disease, you would effectively manage the disease without ever getting the symptoms.

It's much like HIV where we've been able to manage HIV-positive individuals; they never get full blown AIDS and now people live HIV-positive almost as long a life as those who do not have HIV at all. So this notion of being able to both detect it before symptoms appear and be able to intervene at that point as a result of being able to detect it and to prevent its further progression is in a sense what we're trying to do here with Alzheimer's.

But if you have a means of treating this disease later and stopping it or reversing it, even after symptoms appear, I am confident that you're going to get adequate financing and testing capacity. So far no one's been successful and we wish you the best on that score.

I have a question here that I think is really intriguing. It's from Christy Ross and it's, from your perspective, Lisa, what are some of the biggest challenges health care providers face in optimally serving this population, both in terms of talking to people about cognitively related issues generally and how best to communicate with not only the person that may be experiencing some cognitive deficits but also with members and caregivers. It's sort of the problem of how do you talk to somebody about a problem that may be perceived as very threatening to them and potentially a diagnosis that is of a terminal disease that they can't do anything about.

**Lisa Genova:** This is a tough one for health care professionals. I see that, and I saw that when I was shadowing the docs at Mass General. There are a number of things going on here. There's so much fear, and shame, and stigma still surrounding this disease. Physicians are often afraid to say the word Alzheimer's to their patients, and I meet so many people who will tell me, well, my mom has dementia, she doesn't have Alzheimer's, she has dementia. And people are much more comfortable with the word dementia even though dementia's not a diagnosis. Dementia is a symptom. It means, having difficulty with language, memory, and cognition, and it's a hallmark symptom of Alzheimer's disease; it's also a symptom of a bunch of other diseases, and I think people are more comfortable with the term dementia because then maybe it means it's not the Big A.

Interestingly, Alzheimer's has that same sort of reputation that cancer used to have, right? When doctors didn't diagnose people with cancer, they didn't mention the word, families whispered, they called it the Big C and we just didn't discuss it.

So, unfortunately, something like 45% of people who have a diagnosis of Alzheimer's aren't actually told that they have it. This was in the 2017 Alzheimer's report by the Alzheimer's Association. There's a lack of communication going on here, and I don't think it's ultimately what we want. I think if we look back on what has happened with cancer, by way of example, that once we began having an open and honest conversation about the disease, when physicians had the courage to diagnose their patients with the disease and give people an opportunity to talk about what they had, not only with their doctors but with their family members and their community, that conversation then could fuel social change that led to the urgency, the public outcry, the will to demand that we need money for treatments, we need money for better diagnostics, we need money for cures, and we have cancer survivors now. And I think that giving the diagnosis was part of that equation.

And so likewise for Alzheimer's. I understand that it's a tough conversation. No one wants to be told that they have this disease, and yet if we don't say the word, if we dance around it and pretend it's not happening, we pretend Alzheimer's doesn't exist. You know, it's awfully hard to cure something that doesn't exist, and so part of what we're doing with XPRIZE among other things, this conversation with you, George, it's about inviting brain health and Alzheimer's and a discussion around what is real and what is true out into the open. We're trying to drag this disease out of the closet and into the mainstream so that we can show everyone that this is a problem we need to solve. This thing is going to rob twenty to thirty years off the end of everybody's lives if we don't do something about this. We've never lived this long and Alzheimer's—the number one risk factor for Alzheimer's is age so if we're all living into our seventies, eighties, and nineties—we have a very high likelihood of having this disease. And if it's not you, it's your spouse. So, we've got to talk about it. And that includes the docs. They have a responsibility in this too.

**George Vradenburg:** Thank you, Lisa Genova, for your books, and for your wisdom and your great capacity to communicate, and for spending almost an hour with us today.

**Lisa Genova:** You're welcome.

**George Vradenburg:** So, Kristen Cusato, you had a question about how to get involved and we will reach out to you and let you know how to best sign up for clinical research or otherwise to get involved, but thank you for volunteering, we need you, we need an army of people and there are a variety of ways that you can get involved and we'll help you with that.

So I'm sorry, we did have many questions that we didn't get to today but we appreciate your being here. If you have not already joined UsAgainstAlzheimer's please go to <http://www.usagainstalzheimers.org/> and sign up. We will send you a recap of this call, invitations to future calls, and important updates and simple ways that you can get involved. I hope that you will join with us to create a real movement to stop this disease.

Thanks to 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. Please stay on the phone to leave us a message. We are particularly interested in any feedback you might have on this call and ideas for upcoming calls. So thank you, Lisa Genova, for joining us, and thank you all on the phone today for joining us for this conversation and have a good afternoon.