Alzheimer's Talks Transcript
On Pluto: Inside the Mind of Alzheimer's
with Greg O'Brien

April 17, 2015

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

George Vradenburg: Good afternoon. Welcome to Alzheimer's Talks, a monthly teleconference series presented by USAgainstAlzheimer's where we bring you the latest insights from the world of Alzheimer's and reports on the path to a cure. My name is George Vradenburg. I'm Chairman and co-founder of USAgainstAlzheimer's which is an entrepreneurial, non-profit organization committed to finding a disease modifying drug by 2020 and to transforming the fight against Alzheimer's. Our organization is made up of people from all walks of life: researchers, women, Latinos, African Americans, clergy. We have a number of Fortune 500 companies in the industry coalition and we have over 70 organizations in a unified advocacy coalition in Washington called Leaders Engaged on Alzheimer's Disease. We call our organization USAgainstAlzheimer's because we believe that a solution to this disease is only going to come about if all of us, everyone, all of us get involved.

We've been very busy since last month's Alzheimer's Talk. We've kept the pressure on Congress to do its part to increase the funding to stop Alzheimer's. Many of you wrote, called your members of Congress - thank you, your voice was heard. We've succeed in getting a 25% increase in NIH Alzheimer's disease funding in the last few years from roughly 450 million to close to 600 million, but of course that's so far below our target of a minimum of 2 billion dollars a year that we have to keep up this fight but you are making progress. We are making progress, working together. Members of both the House and the Senate have actually proposed prioritizing Alzheimer's research in the Fiscal 2016 budget so we have our work cut out for us every year to increase that funding but we are making incremental progress on this score, none of the other disease categories have made any progress over the last few years because of the pressure on the federal budget so your work is doing God's work. Just in the last month, based upon the British leadership of this global movement in 2014, leaders from 80 countries showed up in Geneva at the first ever World Health Organization Ministerial Conference on Dementia. The dementia issue is one that is occurring in every single country on the face of the globe. So we are now front and center on a global agenda and working on how to sustain that effort across every country to make sure that the work of every country and every NGO, every non-governmental organization, and every industry member is coordinated and works together to accelerate the cure. There was announced in the last month, a 100 million dollar fund in which the British Government as well as six companies have invested in very early stage drug development. It's an important step towards bringing more resource into the early stage drug chain. And just very recently Biogen Idec announced early phase results in a drug that had a 70% reduction in the rate of decline, so this is a slowing of the disease by 70% over 52 weeks as a result of their drug which demonstrated an ability to reduce beta amyloid in the brain and not improve cognition but to slow the decline in cognition in individuals. This drug will be before the FDA in 2020 when they finish the late stage trial and the earlier drug of Eli Lilly, which had similar results, is going to be before the FDA by 2017. So we here at USAgainstAlzheimer's have real hope that in fact we are going to meet our personal, organizational goal of having a drug on the market in the next few years and before the end of this decade.

Just as a reminder, to get the latest updates on all of this, please go to usagainstalzheimers.org, sign up, join. You will get an e-mail every week or so on the latest action you can take to add your name to what is a growing movement that is creating these rapid developments in the progress to get a drug on the market that will help those with dementia and those that are at risk for the disease. We can stop this disease but again, we can't get there without all of us, all of us through USAgainstAlzheimer's and through other organizations working together. Please join us.

We have over 450 people registered for the call today from 46 states and D.C., Puerto Rico and even some international listeners from Canada and Greece. Additionally, about 1,300 people couldn't join us today for scheduling reasons but wanted to hear Greg's remarks so they've asked us that we send them the recording, which you can listen to as a podcast, and also the transcript.

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

Today, I'm honored to introduce you to Greg O'Brien. I'm so grateful that he is joining us today. Five years ago Greg was diagnosed with early onset Alzheimer's, the same disease that stole his mother, his grandfather and his uncle. We're fortunate to be partnering with Greg and in addition to this Alzheimer's Talks, Greg is working with us on our advocacy agenda and will soon be featured in a series of webisodes that we'll be sharing with you in the very near future. Greg is an award-winning journalist and has bravely decided to chronicle his daily fight with Alzheimer's. He has a must-read book, On Pluto: Inside the Mind of Alzheimer's available on Amazon and elsewhere, as well as being featured on National Public Radio and through numerous other media outlets. Greg is bravely shining a light on this horrible disease that for too long was hidden in the shadows. Through his bravery and courage in speaking out, he is hoping to and actually getting the attention of so many people not just all of us everyday folks who are at risk for Alzheimer's or have the disease but also scientists, industry, Congress and regulators and he is inspiring others to get involved so that we can finally tackle this disease with the muscle, the strength, the passion and the urgency that it deserves.

I'm going to open up with some questions here for Greg and then we will open up the questions to those of you on the phone and to the questions that come in online in just a few moments.

Greg O'Brien: First of all, thank you George. It's an honor to be on the phone and to talk to people.

George Vradenburg: Well thank you for doing this Greg. You have a grandfather, a mother and uncle who had this disease. So you saw this disease before you discovered that you have it as well. I'm curious as what it was like for you as a son, a grandson and a nephew to see this disease in others?

Greg O'Brien: Well I first saw it when I was a young kid maybe 10 years old in my maternal grandfather George Brown. My grandfather was a successful New York businessman and very articulate. I noticed when I was a young boy a decline in his cognition. My mom would take me over there with two of my sisters, I'm one of ten kids, the oldest boy in an Irish Catholic family, and we would just sit and watch my grandfather. He wasn't saying much and he was kind of mute and my mother would try to talk to him and my grandmother would take us into the kitchen or into the dining room to do our homework. In time, I noticed more and more decline. Then one day, I came over and all of the furniture in the dining room was gone and there was a hospital bed and my grandfather was in the hospital bed because he couldn't get up the stairs any longer. Shortly after that he passed away of Alzheimer's. I remember going back several days later and the hospital bed was removed, all the furniture was back in the dining room. It was like nothing had ever happened. I knew at that point in my life as a young boy that nothing would ever be the same for me. Then with my mother on Cape Cod, I was the family caregiver and she fought Alzheimer's like a prizefighter and she taught me how to fight it and there are different people who have different levels of fight in them and God gave me a strong level of fight, like my mother, what some of the doctors call a cognitive reserve. It may not be a medical term, but it's like an inherited extra fuel tank of intellect. She fought it and fought it and fought it and I cared for her. There was a time when she just let go and when she let go it was very quick and within 4 months after that she was gone, but she gave me the heart that I have today.

George Vradenburg: May I ask you how it felt as a consequence of that experience to begin to feel the symptoms yourself?

Greg O'Brien: Well the first thing, George, was denial. In my book there's a chapter, it's a great quote from Mark Twain, 'denial ain't just a river in Egypt'. And I was in denial. I didn't want to deal with this and I saw the symptoms coming on and horrific short-term memory loss, not recognizing people and it progressed. It progressed to the point that today 60% of my short-term memory can be gone in 30 seconds. I don't recognize people, including my wife on two occasions, in familiar places I don't know where I am.

I deal with incredible rage. There are times I pick up a phone and I don't remember how to dial. I get so angry, I throw the phone against the wall. Or in my backyard, on Cape Cod, I picked up the lawn sprinkler and I don't know how it works and I know better and I throw it against the tree to break it in a million pieces. There are times when I open my wood stove and my brain tells me that it's okay to touch the glass on the inside, that smoking burning glass, until my hand burns in third degree burns. And there are times when I just cry like a little boy because I don't know if anyone cares.

So I've seen this progression. I saw it in my mother and I saw it in my grandfather and I was there at my mother's bedside when she died and I said, "You know, this is going to end. We're going to start to talk about this."

My background has been as a journalist for 34 years at national and regional newspapers in the U.S. and I promised my mother that I would write about this. In the old days cancer was like the big C, or no one talked about AIDS, and nobody wants to talk about dementia. The Latin roots of dementia sound like a demon howling in the desert and so I said 'you know, it's time that we make Alzheimer's popular because it's taking away a generation'. I fear for my kids and I fear for the children of people on the phone right now and I fear for them. As a journalist, it was difficult to strip myself naked but I said you know, damn it this is the biggest story of my life and how could I not tell it? So I started taking notes and took a thousand pages of notes. First of all writing down all the things I was afraid I was going to forget and then chronicling my mother's progression and mine. From there I wrote On Pluto: Inside the Mind of Alzheimer's. I had help from Lisa Genova. People on the phone might know she wrote Still Alice. The movie just came out and Julianne Moore won an Oscar. And Lisa wrote the foreword of my book.

George Vradenburg: May I ask whether you tried to develop some coping mechanisms, some other things that give you the warning about when you're going to have a quick fall off in either temperament or something? Are there strategies, which at least mitigate some of the sort of spontaneous sense of rage or frustration or loss of memory?

Greg O'Brien: I hate to say that I have an advantage in having Alzheimer's, George, but having seen my grandfather, my mother and just two months ago my paternal uncle, so it's on both sides of the family, I had a front row seat. And as a journalist I've learned to ask questions, so I use a lot of different strategies. Let's say that I've known you all my life and I see you, and this happens to me every day, and I just don't know who you are but I know you're a person of interest. I will keep asking you questions with the hope that you will tell me something about your wife or tell me something about your work that will recollect in me. If that doesn't happen I just let it go and hopefully you know that I didn't know.

The other thing that I use, I have a MacBook Pro, God bless Apple, and I have an iPhone. My MacBook Pro has become my memory. You'll never see me without it. Every time someone tells me something I write it down, in my iPhone same thing. I know people e-mail themselves but they probably don't e-mail themselves 50, 60 times a day and I'll just forget in an instant. It's like someone turns a light out in your brain and I will be afraid that thought is going to go, so I'll e-mail myself. And you have to have a sense of humor. The only way I get through Alzheimer's is with faith and I have faith in God and humor and hope. So sometimes on a Friday I say, this is a weekend, this is great, I can finally relax. I'll look at my inbox and there'll be 50 freaking e-mail messages. I'll panic and then I'll realize that 45 of them are from me. But those are the strategies, among others, that you use. Another strategy is tremendous exercise and exercising the brain and the body every day.

George Vradenburg: You mentioned humor, what is it that you find humorous?

Greg O'Brien: Well you have to laugh at yourself and also I laugh at this demon called Alzheimer's because I don't want it to have power over me. At the same time, I know it's going to overtake me. I have this saying in the book, and I can't say the word that I use in the book, but I say these demons don't know who they're screwing with. I learned as a young man, maybe it's my Irish roots, to laugh in the face of trials and laugh in confidence, you laugh in faith and you laugh in hope, and you don't despair. I've said in my book that lying down, whether it's in football or wrestling or soccer, is a position of defeat. We all have different strengths in terms of what it takes to stand up and what I'm urging people is whatever God-given strength you have to fight, fight with all the muscle you can. And fight with humor, laugh at yourself, laugh at this disease. Again it will take you out at some point.

George Vradenburg: Do you still get daily pleasures with your wife or with your kids, with other daily stuff? What gives you some pleasure, some hope?

Greg O'Brien: I know people who are listening, a lot of them know firsthand, this is a disease that you have to fight 24/7. There's no rest. I find that if I'm not pushing forward, I'm slipping backwards. I take a lot of medication and I keep propelling myself forward and I have my doctors tell me, "Slow down. Don't use up all the reserve." But I find if I don't go at full throttle, I'm slipping back.

The simple pleasures that I have are the love of my family, walking on the beach, one of the biggest pleasures I have is in writing because that's really who I am and I've written all my life and I fear the day when I put my hands on the keyboard and I don't know what to do. That's the day when I'm going to want to leave this planet. That's when I'm most at peace is when I write because that's my soul, that's who I am. I've learned that I used to trust my brain and my brain was my prized possession and now I don't see any chance for reconciliation. But I've learned to write and speak from the heart. I believe with all of us there's that journey from the cradle to the grave where we seek that place of the heart. I'll ask a question of people on the phone, anyone who doesn't think they're going to die someday, would you raise your right hand now? And so we have to get to that place of the heart because that's what I believe is a soul and that's what survives and when I can't speak and I can't recognize anyone, in my soul, I'll still be who I am and I told that to my mother and I think that kept her going.

George Vradenburg: You mentioned the love of your wife and your children. Can you talk a little bit about what you see has been the impact on them of you having this disease?

Greg O'Brien: Yeah. The hardest thing is telling your children. I was with my wife when I had the brain scan and the clinical test and I flunked all those. I also carry the marker ApoE4 on both sides of the family so the deck was kind of stacked against me. But when I knew what it was, when someone said it's Alzheimer's, I was somewhat relieved because now I said, "Okay, this is the enemy. I've seen this enemy before I saw it with my grandfather. I saw it with my mother, my uncle has it now and I'm going to put all the effort I have into fighting this enemy."

And you know, I just forgot the question you were asking me and I told you this would happen, George. Could you just repeat the question? Because this is what happens. Remember what I just said because I'm not going to remember, but I try to simplify Alzheimer's. I don't know if the people who are listening how many of them have basements but I always ask the question, do you have a basement? If you have a basement, do you do your laundry in the basement? Have you ever done your laundry at night in the basement? Have you ever been in the basement when someone in the kitchen doesn't know you're down there and turns the light off and you're in a panic and you're really angry and you yell and you scream and then they turn the light back on. That's kind of Alzheimer's in the early stage, on and off, and on and off and you don't know when it will go on and off and it scares the crap out of you and then at some point, the light goes off and it never goes back on again. And now you have to tell me the question because I forgot it.

George Vradenburg: I was asking about the impact on your family of you having this disease?

Greg O'Brien: My wife was there when we got the diagnosis and I held her hand and I was in shock but I knew. I just remember staring at her and I felt just around the sides of my eyes the tears rolling down. I knew where this was going and I couldn't fix it. I've never been a fix it man, I used to fix everything with duct tape and I'm sure people listening know what that is and I used it for everything. I couldn't even fix Alzheimer's with duct tape.

Then we had to tell our children and I remember having them come back to the house under the guise of taking them out to dinner. I'm in the bathroom preparing to talk to them and really nervous and I felt like Luca Brasi in the Godfather you know on the day of your daughter's wedding and I didn't know how to say it. So I go out and the first thing my son said when I told them was, "Wow, that explains a lot." And then my youngest son said, "Well dad, you're losing your mind." And I said, "Well to some extent." So that's the first level but then denial takes over and if I could just tell another anecdote here which I think is very poignant. A week later we had a family vacation out in Coronado near San Diego. It was a family reunion and my son and I got there earlier and I've had to turn everything over to him as power of attorney and my wife as well. He needed to see the paperwork and so we went to dinner and we're standing on a balcony overlooking paradise all of these lush tropical trees and flowers. I showed him the power of attorney papers and he didn't want anything to do with it and I won't go into it, it was a carpet bomb of F bombs. I said, "Brendan you know, you've got to see this" and he threw back a bunch of swears, and I said you've got to see it. He was very angry and then finally I went into the room and I brought out my medical records and he didn't want to see them and I started reading and he kept saying, "Dad, this is bullshit. This is expletive bullshit." And I said, "Brendan, you need to read it." And all of a sudden he grabbed my medical records, he ripped them in a million pieces and he threw them off the balcony and he said, "This is bullshit. This is expletive bullshit." And then, he turned to me and he said, it's bullshit because I know it's true. He was 28 years old and he put his head into my chest and he cried like a little boy. And that was our moment and I think sometimes in Alzheimer's you get to that moment. But the humor, and God has given me humor, was the next morning I wake up at 5:00 am and realize that all of my medical records saying that I'm losing my mind are spread out over paradise. So I went and I got a trash bag and I went down and in the lush trees and the beautiful flowers I was picking out pieces of my medical record that said that I was losing my mind, putting my history in a trash bag, and that moment wasn't lost on me.

George Vradenburg: You described you know the path, you know what's going to happen. Have you considered suicide?

Greg O'Brien: Yes. And there was one time that I tried it. I have prostate cancer and also sometimes in Alzheimer's the body breaks down, I was diagnosed recently with Acute Spinal Stenosis and Scoliosis and I deal with depression. Having said that I feel almost like Lou Gehrig, the luckiest man on the face of the earth. But I had the fifth prostate biopsy and something went horribly wrong and I started bleeding, hemorrhaging, and I didn't tell anyone. I didn't tell anyone for 3 days and at the end of 3 days I had bled out close to 8 pints of blood, now your body only holds 10 and I remember because I thought this could be my exit strategy. I am not treating the prostate cancer because that is my exit strategy and I may change my mind but we don't have a cure yet and maybe we will but I don't want my wife and my children to see me in that final stage, having seen my grandfather and my mother, to put them through that. I remember lying on the couch at midnight on Cape Cod and you know, I'm not here to proselytize George, but I felt then in my heart and people can define God differently, but I felt that the Lord said, "Hey pal, you go to sleep tonight you may not be waking up and you don't have the right to take your life." And so, at 12:00 having lost 8 pints of blood I got in my jeep and drove 20 minutes down to Cape Cod Hospital. I went in there and they took one look at me, and inside the hospital I lost another 750 cc's of blood, and it took them a while to figure out how to stop it but they were able to control it. They kept me in the hospital 3 days. They gave me 6 pints of blood and told me I'd make up the rest. Finally a nurse came in the next day to scold me because they knew that I was trying off myself and she said, "Do you realize Mr. O'Brien you're supposed to be dead." To which I said in my Irish humor, "Yeah, but no one had the courtesy to tell me."

And from that moment I've never looked back. I said okay, it's not my place to take my life. So I've felt that there are things that I'm supposed to do. And I got to tell you this, I may sound good on the phone with you but I said before my brain is like an iPhone, it's a sophisticated device but it has a short-term battery, it pocket-dials, it breaks down, it gets lost easily and I'm seeing the progression and it's scaring me. I don't necessarily see much beyond 4 years or so or a couple years but I’m determined that I'm going to make them the best years of my life and in that process I'm going to bang the drum to find the cure to kill this monster.

George Vradenburg: And so I guess I should ask you, what are you trying to do with your speaking out? What do you hope that people will do as a consequence of your speaking out?

Greg O’Brien: Well as I've said, the Irish never get mad we get even. And I'm getting even with Alzheimer's. And I'm not getting even for me, because I think the train has pulled out, but I'm getting even for everyone on the phone and I want people to understand that Alzheimer's is not your grandfather's disease. Yes, my grandfather died from it but it is a disease that can take 20 years or so to run its course and sure there are people in their 80's with Alzheimer's but in many cases, the symptoms started 20 years before and these individuals are scared to talk about it. They're scared that they'll lose their jobs. I've known people who have had the symptoms and they have lost their jobs and it's a scary thing and it takes all of us collectively to start to speak out and to say that you know for a period of time you can live with this disease. Yeah, you're a little less of who you are and yes, things are going to progress but there were people who are scared. And in Still Alice, it's a fictional character Alice Howland, in Lisa Genova's book she's teaching at Harvard. Well I gave a speech in Cambridge not long ago and two Harvard professors came up and they said to me, "I liked your book. It was right on target and your speech was on target." And I said, "How can you say that?" And they said, "Well, we're both still teaching at Harvard. We've been diagnosed with early-onset Alzheimer's." At speeches that I'm giving, I always ask, "Anyone with early-onset, stand up." And sometimes 15 or 20 people in the audience stand up. They've been diagnosed. We have to find a way to respect these individuals, to give them their dignity because they're afraid to talk. And maybe as a journalist I've learned how to tell the story and shame on me if I don't but I got to tell you George this is not an easy story to tell. It's not easy to strip yourself naked.

George Vradenburg: What would you like people to do as a consequence of hearing you talk?

Greg O'Brien: Well I think what we need are resources and particularly the focus of USAgainstAlzheimer's. I think we need collectively through USAgainstAlzheimer's to reach out to our government officials and say we need to appropriate the money to find a cure. And George you know this better than me, maybe when I'm finished with the sentence here you could tell people how Alzheimer's pales in comparison with funding for other diseases. Care is important okay, but if we don't have a cure then we're just going to keep caring and we need to get to the point where we have a cure. We can't forget about the caring part and the caregivers and we need all that but damn it, we have to find a cure and the only way to do it is with resources. There are wonderful things being done but you know George maybe you might want to jump in and talk about how Alzheimer's pales in comparison in funding.

George Vradenburg: Well I'll take 30 seconds because I think this group that we have on the phone is familiar with this. The NIH invests something less than 600 million, it's in the 500 millions against this disease every year and HIV/AIDS has about 3 billion dollars investment every year domestically and 6 billion dollars from the U.S. government into global funds and cancer has about 6 billion dollars invested domestically. We now know that the number of people who die as a result of this disease is about equal to the number who die of cancer and heart disease every year. We know now that the cost to society of this disease is 50% greater than the cost to the society of cancer, and we know HIV/AIDS has become a manageable disease and that's because we've invested in those disease categories. We're making progress against cancer, we're making enormous progress against HIV/AIDS and making enormous progress against heart attacks but we're not making progress against Alzheimer's because we do not invest adequate resources against it. But I will get off my high horse.

We do have some questions here from people. Our first question is from Carol Roberts-Wilson in Merritt Island, Florida. Carol, would you ask a question?

Question: Yeah. Well, I know that Mr. O'Brien talked about some strategies that he is using but what I'd really like to know is if you're taking medication, is it helping or it is not helping and why take medication if it really doesn't help?

Greg O'Brien: I should tell you on medicine, the most I ever did in high school was cut up a frog so I'm not a doctor but I'll just tell you what I take. I take 23 milligrams of Aricept, 28 milligrams of Namenda, 30 milligrams of Celexa to try to control the rage and they gave me 50 milligrams of Trazodone but I don't take it because it makes me loopy. I have found over time that has kept me balanced and in my work I have to try to multitask as much as I can and I haven't been able to do it without the medication. However, I'm finding and I've asked doctors about it recently, the medication having less and less of an impact and George may have some thoughts on this because I think sometimes when you take medication to a point you can become immune to it, does that make sense to you George to answer this woman's question?

George Vradenburg: Yeah, I don't know if you've become immune or whether the disease simply overwhelms the medicine but in fact the medicines were only tested for up to about 2 years and their labels say that they are effective for a limited period of time but some people have been taking these medicines for years and finding that while their potency decreases they still think that they get a benefit through time. There seem to be no side effects of continuing to take Namenda and Aricept for lengthy periods of time. So it's sort of like if it does some good, if it controls some rage, if it has some benefit why not take it because there don't seem to be any adverse side effects.

Greg O'Brien: It's doing some good with me but less than before so in line with what George said, I still take it, it doesn't have any noticeable side effects with me.

George Vradenburg: We have a comment from someone online, Jennifer Eads: "Thank you for this candid insight Mr. O'Brien, let's go kick Alzheimer's a$$"

Greg O'Brien: Amen

George Vradenburg: Sharon, do you have a question for Greg O'Brien?

Question: Yes, thanks, I do. Well, as you know there's a lot of research going on and there are some drug trials and I'm wondering Greg if you have participated in any of those?

Greg O'Brien: Not as of yet because I've been relying on the Aricept and Namenda but as I've noticed it's had less and less of an impact I'm far more open to that now and we'll be discussing that with my doctors and that's a good point to bring up because if the medication you're on ceases to have the impact that it had before it's time to look at other things so that is a good point.

George Vradenburg: We have a question here from Richard Morgan in North Huntingdon, Pennsylvania. Richard, would you ask your question?

Question: Yes, Mr. O'Brien I'm intrigued by your book, a wonderful book. I deal with people with Alzheimer's. I wish you would say more about why you chose the planet Pluto as the title of your book and Pluto seems to be a place for people with Alzheimer's. I love your concept that the right side of the brain is intact. Can you say more about that?

Greg O'Brien: Sure and I'm happy too, and I probably should have mentioned that before. When I was a young reporter as an investigator reporter, I've worked for newspapers across the country in Boston, out west. At the time, I was at the Arizona Republic and there was a lot of organized crime out there I was covering Joe Bonanno when he had so called retired out there but not really and so when I talked to sources off record, I was fascinated with the planet Pluto, why I don't know, but I would say we're going to go off record and I'm going to take you out to Pluto where no one can hear what is said. People would laugh at that but they realized because I had a record if I went off record I kept to it. And then later in life with my buddies, you know we've all been there whether men or women you go and you talk socially about things off the record, the unmentionables about life, and my buddies would say, "Are you taking us out to Pluto again?" and I'd say, "Yes." I became synonymous with this planet Pluto and when I went into the stage of Alzheimer's, as I said before, and anyone who's gone through it will know what I'm talking about, it's a 24/7 fight you can never let your guard down but there are times when you get tired and you just drift out and I had to come up with the name of a place that I was comfortable with when I would just drift out. My family would notice. My wife and kids and they said, "Hey dad, come on back" and so I started saying well I was just out on Pluto and I say in my book that my grandfather has been to Pluto, my mother has been to Pluto, my uncle has been to Pluto, I've been to Pluto and there's going to come a day when I don't come back and I want people to know where I am and so I use the word Pluto that way.

You had asked another part of the question and I have to tell you sir I forgot so could you just tell me the second part?

Question: Yeah, I was asking you Greg about the right side of the brain is intact even when the left side fails. That is very profound.

Greg O'Brien: Yeah and again I just cut up frog in high school. If there any doctors, I am in awe of all doctors and nurses and medical people. I do think at some level that those with Alzheimer's may know a little more about the disease and how it affects people than those who are studying it because we're dealing with it and so it just gets back into the fight against it. Every day you have to get up and do battle. You know water seeks its own level, and the left side of my brain, the business, the functional side, spatial I can't judge spaces anymore, I see things that aren't there. All of that is in recession, but my soul who I am. We're all different people, I'm a writer, I communicate and I got to tell you when that is gone, and maybe that's what happened to my mother, that's when I'm giving up the ghost.

Again what I tried doing in On Pluto is to simplify Alzheimer's. It's really the first book written by an investigative reporter embedded inside the mind of Alzheimer's chronically the progression of his own disease. But I thought of my brain before as a big garbage pail and you know when we grow up we throw all sorts of crap in there that really we shouldn't no one really cares, trivia and all the stuff like that. In Alzheimer's your ability to process decreases and the brain atrophies and so now I think of my brain as the size of a flower vase but I believe, and again I could be wrong, I believe to some extent we might be able to re-circuit parts of the brain and if you've been gifted, and I feel that I have, with the cognitive reserve, at times you can pick and choose what you put in that flower vase to survive for the moment until it takes you out. So my strategy here is to let the other things go, don't sweat it but with my writing and my communication fight like hell everyday against that and that's an ongoing fight but the other stuff on certain days it's in a freaking free fall and you know it scares the crap out of me.

Another thing, these series of blanks, the lights going on and off. I gave a speech two days ago up in Maine to 500 people, and I could speak to 600,000 people that doesn't scare me, but the ability to deliver is important. 45 minutes before the speech the light went off. It's like someone in the kitchen turned the light off, I'm in the cellar and I couldn't think. I wasn't sure where I was and I knew I had to give a speech. So I texted my wife and my kids and friends and I said, "Do me a favor. Say a prayer for me." People around me knew that I was in trouble and this gets back to the cognitive reserve, it gets back to reaching into the heart and soul and I said, "I don't know how this is going to happen but when I get up to the microphone it's going to happen." I got up and I apologized to the audience and I told them what was going on, I lost my place 7, 8 times during the speech but delivered the speech and when I was through 500 people stood up and applauded. And they weren't applauding for me, they were applauding for them and the fight in them. I got to tell you that made me feel very good walking out because they were saying, "You know what we can fight this too." That's a long answer and I'm sorry it took so long to get to it.

Question: Thank you.

George Vradenburg: Richard is an editor of a book that we published called, Seasons of Caring: Meditations for Alzheimer's and Dementia Caregivers by people of 14 different faiths traditions to talk about what you treasure so much, and what we all treasure so much, and that is our soul. So we're grateful very much to Richard Morgan for his role in helping us edit that book and to put out now to the world the ability to talk about this disease in terms of your soul and your spirit and your mind rather than just as a disease and some chemical interactions in the top part of our bodies.

Greg O'Brien: Well thank you, Richard.

George Vradenburg: Let's go to Carla Denici from East Rochester, New York. Carla, you're on the line here.

Question: Yes, George, great respect to you and also to Greg. Thank you so much for sharing your story and also thank you for interjecting faith in there and God as well because I've always acclimated mind, body and soul with my mother's condition as I fought with her for 20 years to battle the disease.

What I do want to say, and I have not heard it mentioned yet, is what we need to do is to continue to rally behind and push behind the doctors and researchers that are really making some progress with things that are potentially valid and that have the least side effects. One of them is Doctor Suzanne Craft. I know that USAgainstAlzheimer's has done teleconferences on her work, she's having some issues right now with the delivery system for the nasal spray, she needs help so we need to rally behind her. Doctor Schubert, who's pushing for J147, he's got no help, he's ready to go into clinical trial stage 1 but he can't get the funding. There are so many potentially valid compounds that are coming up and that can't get into trials and that show promise and that show potentially less side effects but they don't have the push that they need and the only way we're going to have progress is if we push. So the caregivers as well as the inflicted need to get behind these doctors and these researchers. They're thinking outside the box, I mean we've looked at the amyloid hypothesis for many years now, we know we haven't got anywhere. We need to think outside the box, I said this many times but I'm going to continue to say it, and look at the underdogs that are looking at different methodologies and different approaches. You know as well as the newest one that they just have in the news about the new system. They've discovered some implication which I've always know but now they discovered it and showing some progress with that, I believe it's the DMSO into clinical trials. So this needs to be rallied around and pushed for so that people like Greg, people like my mother, potentially me, my brother whomever is going to be afflicted. We need to help those who need it.

George Vradenburg: I would say in this spiritual sense that we've just been talking, Amen. Fighting both for the public funding needed but also for some innovative financing mechanisms that would invest in the companies in this space. So you're right on.

Question: Thank you.

George Vradenburg: We've got a couple of comments from online. Michael Ellenbogen, who is a person with Alzheimer's who recently went with me to the World Health Organization Meeting in Geneva and was so articulate about the perspectives of those with the disease in front of 80 nations, has reminded us that we should be looking at clinical trials not just for ourselves but to help others. In a sense it is a legacy that all of us can have for our loved ones or indeed protect ourselves but for our loved ones and family members who are at risk as well. To participate in clinical trials so that we can get the drugs to market that can be effective both for people who actually have already been diagnosed, like Greg, but also for those who are at risk, where we might be able to delay symptoms long enough so that you never get the symptoms much like HIV which we now control and manage because we can prevent AIDS but we manage the HIV virus. Michael has also made a comment that I should read, because he is a person with dementia like yourself Greg and he said, "I'm so proud of Greg to actually speak up and say what most are afraid to say, the dark side, it is so important for people to understand what we're dealing with daily. Greg is so much like me." So you're speaking to a number out there in the audience.

Greg O'Brien: Thank you. Thank you very much.

George Vradenburg: Michael is an exception like you who is speaking out but there are so many out there that, as you say, get into denial or hide, out of embarrassment or prospective embarrassment. Your story about speaking to 500 people and not being afraid to be embarrassed is perhaps very insightful on what we need to do not just as people with dementia but caregivers as well.

You know that's an interesting question. Let me ask you, can you give caregivers some advice about how best to be supportive of you and of those with dementia?

Greg O'Brien: First of all, I have the unique perspective of being a caregiver and then someone with the disease. So I've been able to reflect. I would tell you that the caregivers, and I know there are a lot of them on the phone, they are the heroes of the world. People like me, and Michael, and others we're going to forget someday. But these individuals are going to remember and they deal with depression and they deal with health issues and part of the cure and part of the effort moving forward needs to be to take care of them and not to overlook them because they're dealing with a lot and I think they get over looked. So my heart goes out to the caregivers.

Having said that, what I find with me simple things like, love or touch. Just a simple touch, it's not a heavy hand, but just sometimes when I'm down and someone puts a light hand on me, it just boosts me up. Another thing is let's say I'm in my office here and I'm looking at the walls and they're white. Well it may come a day when I'm talking to someone and I talk about the blue walls, when they're white, and they're only going to be blue because I can't find that word white and I'm going to say blue. What I would say to caregivers is: what does it matter whether it's blue or white. Let it be blue. If you keep correcting me, I'm going to know probably that I was wrong and your correction of me is going to make me feel worse about my self esteem and the disease because I don't know the difference between blue and white and it's going to make me angry. So let it be blue. I think it's a difference with maybe a spouse whose wife or husband died 10 years ago and they think that he or she is still alive. I think at intervals that you have to correct that but on the little things let it go. Also try to, as I said before, we're hearing a lot about which I'm so thrilled about this conversation because it's going in the direction that I'm going in is learning to speak and live in the heart and the soul and I believe that you can communicate with people. Can I tell one story about my mother, George we have time for that?

George Vradenburg: Yes, sure.

Greg O'Brien: This gets back to always talking to someone. One of the toughest days was when I had to take my mother to the nursing home because she wanted to stay at home and she slid quickly. One night I got a call from the nurses, and I just lived 2 miles away from the nursing home, and they said, "Your mother is really scared. She needs to talk to you." So I went down 9:30, 10:00 at night and she's lying in bed and my mom is 5 foot 1, 104 lbs - that's after having 10 kids and 5 miscarriages. So she's just this little Irish woman and she's lying in bed and I woke her up and I said, "Mom, I'm sorry to wake you up." and she said, "No Greg, I'm glad you're here." Well that was the first time in 4 months that she could recall my name, and I don't know if anyone has been there in the moment when someone passes but there can be continence to them and I felt at that moment might be at hand. I had put a photo of my grandfather George Brown at the foot of her bed so my mom could look at that and I felt, I don't care what anyone says, I felt his presence in that room and my mom for the first time because we were speaking to each other's heart. We didn't talk big things, we just talked little things but we were connecting in the soul, in the heart. She closed her eyes, George, and this is hard thing for me to talk about, excuse me, it's just difficult, she closed her eyes and I kissed her on the forehead and her little eyes opened and she said as plain as day "Greg. Where are you going?" and I said, "Wow, the moment is at hand." I grabbed my mother's hand and I said, "Mom, I'm not going anywhere, we're riding this one out together." I sat down and I held her hand until she fell asleep, I kissed her on the forehead, and she never woke up again.

I always tell people, please never stop talking to people in the heart and in the soul. Ever if you can't get through the brain you can get through the heart and the soul and maybe this is one way that we can show Alzheimer's that we're in charge not Alzheimer's.

I'm sorry to get so upset about it but it just pisses me off this disease.

George Vradenburg: That is a powerful note that we are going to end on. Thank you so much, Greg. As I mentioned at the top, we are going to start a series of webisodes with Greg. So that he can regularly report on his experience as he goes through the experience of this disease and do it hopefully on a relatively frequent basis perhaps monthly, perhaps more frequently, we'll see how it goes so that we can all in a sense be with Greg as he experiences this disease and so we can take from his strength and his bravery the motivation to do more to stop this disease.

I have a close friend named Meryl Comer who has written a book as well about caregiving, Slow Dancing with a Stranger: Lost and Found in the Age of Alzheimer's and she says how important it is to take the pain and take the experience to turn it to purpose. So that's the great gift that Greg is giving us all is to take his experience and turn it into purpose for him and for others with the disease or at risk for it.

Thank you Greg very much for your bravery, your advocacy, we're honored to be working with you, to give you your voice, to spread your voice and to take power and strength from your voice as we continue to fight this disease.

A number of you have written and asked the question: What can we do? What can we do to take from what we've heard today and to be more active? And I encourage you to join USAgainstAlzheimer's. Just go to usagainstalzheimers.org and 'join us' because what you will get is every week something you can do. It will take you probably 15 seconds a week to actually click on something to add your voice and while you think that your voice is not going to add influence or power, recognize that your voice is being magnified tens of thousands of times over by others who are clicking on the same thing, exercising their voice and my wife and I and our team basically take the strength that volume of voices gives us and we take it into the halls of Congress and we give voice in very concrete ways to members of Congress and the Senate.

At one point, one of the senators said to my wife, I don't get into disease specific, I don't invest in particular diseases. My wife said, "Well if the generals came to you and said I want 600 billion dollars for national defense and said we know more about national defense than you." Would you not question them? Would you not understand the strategy? Would you not understand some national priorities? And he said, well of course we would and we said, well the same thing holds here. We need a clear national strategy to get at this disease and you may not decide on particular grants or scientific theory but we need you to take leadership. After several conversations over several months, he called her one night and said, you have worn me down and I'm now on your side, what can I do? And so it's a combination of your strength and your voices and our nudging or worse here in Washington that will basically cause Congress to begin to change its mind and it is beginning to change, slowly not fast enough, they are not scaling fast enough but they are moving for the first time. So thank you all for participating. Join USAgainstAlzheimer's and we will take your voice into the halls of Congress.

Just as a reminder our next call is on Wednesday, May 13th from 3:00-4:00 Eastern in partnership with the National Endowment for the Arts. We're going to have a panel of experts on poetry and storytelling and a discussion of the benefits of the use of the arts with persons with dementia or their caregivers. We also may be announcing a new network among our women, African Americans, and researchers of artists who may take up the cudgel against Alzheimer's. So I hope you'll join us next month for that discussion. As always stay on the line if you'd like to leave us a message or a question or comment. We're always interested in what you would like to discuss on future calls.

We thank you Greg for touching our hearts, our souls and for inspiring us to do more against this disease every day.

Greg O’Brien: It's been an honor to be part of this and to be with this group listening today and I thank you for this opportunity for everyone who's listening. Thank you very much, you've given me strength.

George Vradenburg: Thank you all for joining us today and have a good afternoon. Bye.