UsAgainstAlzheimer's

Alzheimer's Talks Transcript
Before I Forget
with Dan Gasby
January 26, 2016

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

Welcome to Alzheimer's Talks, a monthly teleconference series presented by UsAgainstAlzheimer's where we connect you with leaders who are working to stop Alzheimer's. My name is George Vradenburg, Chairman of UsAgainstAlzheimer's, which is an entrepreneurial, disruptive, innovative organization that's really transforming the trajectory of this disease.

Thank you for joining us today to hear from Dan Gasby. He is the partner in building a high-profile lifestyle brand, married to B. Smith, the incredible women who broke down barriers as a restaurant owner, and model, and is now facing the challenge of her life, Alzheimer's disease.

Together Dan and B. have written a heartfelt and amazing book entitled Before I Forget: Love, Hope, Help, and Acceptance in Our Fight Against Alzheimer's. If you have not already read this book, I really encourage you to get a copy for yourself and anyone in your life who is facing Alzheimer's. They outline in great detail the challenges that come with caregiving.

Thank you so much to Axovant who is sponsoring this call. Axovant is currently enrolling a clinical trial called MINDSET, which you can learn more about on their website: http://www.alzheimersglobalstudy.com. Axovant is actively seeking registrants for that trial, particularly African-Americans.

We have an amazing response to this call. We have close to 550 people registered from 42 states, the District of Columbia, from Canada, and another set of people that signed up for our recap materials.

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

I would like to begin by reading a comment that we got before this call from a listener from New York about B. Smith. It just really captures her personality and her style and I think it starts us off on a good tone for this call. This is the comment:

"Long ago I had dinner at the lovely Mrs. Smith's restaurant. I will never forget the energy that came from this amazing person. She embraced me and welcomed me to the restaurant and floated about chatting with her guests, spreading a sense that they were all her very special, honored guests. She treated everyone in a beautiful way that I have yet to experience again in any business environment. I see her as a truly great role model for what internal beauty really is because her inner self was outshining her stunning appearance. I hope she knows that now, that she has been this person to me and I am sure to legions of people. She has earned love, so now we can show her some love without sadness or shame."

You have a remarkable wife Dan and she has a remarkable husband. I would love to have you just describe a bit why you wrote your book with B. about your experience with this disease and take a moment to share some background about B.'s career.

Dan Gasby: First of all, thank you George. I know that you've been a tireless advocate for trying to figure out to make this dreaded disease, put it in the rear view mirror of our society. I want to commend you and the African Americans Against Alzheimer's, LatinosAgainstAlzheimer's, for what you're doing.

To put it succinctly, what you read and what people meet when they first see my wife is what is true. She is the most kind, decent, person. I can truly say that I've never had her say anything but positive about some of the worst people in the world we've ever dealt with. That's just the spirit that she has that radiates, so thank you for saying that because I think it sets a great tone about who and what she represents.

The reason sweetie and I - I call her sweetie - wrote the book, was because both individually and as a couple, we've always believed that the shortest distance between two points is not a straight line, but the truth. We've never hid from anything that we've ever done, both individually and now as a couple for the past almost a quarter a century, actually counting dating, a quarter century. Sweetie was a candy striper. When she opened her first restaurant on 8th Avenue and 47th Street in 1986, it was a far cry from what it is today. It was right out of Midnight Cowboy, you had all types of miscreants. The only suits that you basically saw at night were shiny suits. There were pimps, and hustlers, and pickpockets and everything that you can imagine.

She opened with a vision to bring a diverse group of people black and white, yellow, red, all under one stylish umbrella and for 28 years she did that. What she also did was she understood that a restaurant is a community center and a center in the community. No matter what the cause was, she would always try to find a way to open the restaurant up so that people could get out what they felt was important about social issues, whether it was dealing with children who were abused or for reading or whether it was a group that did HIV testing for women who were working on the streets or a major movie. It didn't make a difference, she treated the grandmother and the President of the United States the same way. The book is just a natural extension of what her personality represents and honestly, what my personality represents because she doesn't belong to me. She's always had this ability to project what's right with us as a people and what's right with this country because where she came from, from western Pennsylvania.

When we finally started to see these little signs of difference and found out what was ultimately a diagnosis of Alzheimer's, we realized there's only two things you can do, you can stay silent and not try to make a difference, but at the end of the day, if you know who you really are you would regret that for the rest of your life or you could try to make it better. My father always said, "If you get a hand you have to play, play it to win." What we realized was it was better to talk about Alzheimer's because there are so many stigmas and particularly in the African-American community that we don't want to talk about, whether it's homosexuality or AIDS or what have you. This thing called Alzheimer's is a big no-no and so we wanted to let people know that if B. Smith could have Alzheimer's anyone could get it and now how do we figure out how to make a difference. That's why we wrote this book and it's a brutally frank and honest book.

As a caregiver, the one responsible for taking care of my wife. Literally, my wife could do everything. To see her go from, say on a scale of 0 to 10 and 0 to -10, to see her go from be a 9/9 or 10 and to go to -7 or 8 is a dramatic thing. During the course of that, I couldn't understand because I sit there and I look at a women who was in her mid 60s that looked like she was in her mid 40s who has a resting heart rate of 67/68 and blood pressure of 117/74, she's in a world class shape from the eyebrows down, but she had these little problems, these little signs, whether it was an outburst that she never exhibited or whether it was repeating things that she never did or whether it was just things that just didn't make sense to me by how she did them or the time she took to do them, it was something that we went through. We had blow ups. I thought at one time she was tired of me or the relationship had grown stale because I couldn't understand it. When we look back on that whole scenario of things, we realized we need to tell the story, because it would be a shame that other people could go through the same things and not know that it's not sociological, it's not psychological, it's physiological, it's a disease and so we said, "Let's tell the story and try to make a difference."

George Vradenburg: Dan, you mentioned stigma and there is a continuing stigma about talking about this disease. Why do you think that stigma is greater in the African-American community? Why is it such a no-no to talk about?

Dan Gasby: I think it's historically we don't bear what we've done to other people because we've had to overcome. That whole notion of you don't want to show any faults. You don't want to show anything that represents failure or something that makes you less. You want to be stoic. You want to be strong. You want to overcome what the system has given you, but in the process of doing that, what you ultimately do is you undermine the very things and the very forms of help that you need to actually overcome those things. It's sort of working in direct opposite to what you really need to get something accomplished.

George Vradenburg: How did you two meet?

Dan Gasby: It's funny you should ask that, 29 years ago coming up this Valentine's, I was in her restaurant at the time and it was Valentine's Day. To make a long story short, what I did was with the date I had, I ordered all of the items on the menu before she came and when she came in I said to my date, "I've taken the liberty of ordering your salad and roses," a dozen roses came. "I've taken the liberty of ordering soup and a bottle of Chanel #5." It was really hot back then, Chanel #5, there's so many cologne and perfumes now. I said, "Seafood was particularly delicious and a pearl necklace came. The waitress thought I was a nice guy, a great guy and she told B. about me and as God is my witness, I remember like yesterday, she had this red hostess gown on, fire engine red with a red bustier and she looked like chocolate and strawberries. That's the only thing I can tell you. As she came closer, you know how you have those 3 pull switch lights, where each time you pull it, it gets brighter and brighter? It looked like every step she got closer the light would beam more. Then she hit me with what I call the Michael Jordan smile. Nobody has a more beautiful smile than she does and when she smiled, I said to myself, I wasn't thinking about dating her or anything like that, my first reaction was, "Man, I wish I had somebody in my family like her."

One thing lead to another, she got married, I was married. Then my wife left me, she got an annulment, and as luck and fate would have it, I had a TV show that was called Big Break with Natalie Cole and it launched the career of R Kelly and a guy named Eric Benet, and they canceled the show two weeks before Nat King Cole's and Natalie sang that classic duet "Unforgettable." I was depressed because it became song and album and billboard of the year. I walked into the restaurant and she asked me, "I hear you're going through some troubles with your show." I said, "Yes." I said, "Would you like to go to a movie?" She said, "Sure." We kept missing each other and what happened was one day I came in and missed her and she came upstairs while I was in the restroom and she was getting hugged by a guy so good looking I would have dated him and I'm not gay or bi or anything. I said, "She's got too many guys chasing her," and I walked out the door and gave up.

Four months later, a white jeep drives up to a little bistro on the upper west side and two incredibly beautiful women jump out, one had a double breasted blazer and jeans, the other had a triple breasted blazer and an ensigns hat, a naval officers hat and it was Barbara. I asked her for a hug when she walked in the door and she gave me a hug. I asked her for another one and she pushed me back and says, "You know your life might make a turn for the better if you make a phone call sometimes." I called her, and I said to her, "Can I come by and have lunch with you at your restaurant?" She says, "We can never talk. I'm always on 24/7 when I'm there." We went to a little bistro up the street called Café Cello, no longer on 8th Avenue, and I fell in love with her right then and there. I didn't know what to do, so I wanted to take her to my health club, because it was a state of the art health club. It had Nautilus equipment, so you can imagine how long ago that was. She was wearing an Annie Hall outfit with sneakers and a big brimmed straw hat with a black band around it and the only thing you could see was her eyes and her smile. We walked to 51st Street and 7th Avenue and she kissed me on the cheek and I walked about maybe 8-10 steps away and I turned back and she was staring at me, and we've been together ever since.

George Vradenburg: That's quite a story. You very interestingly see the world in visual terms and see that woman in your life, now, very visually. That's a terrifically told story about a wonderful way of falling in love. You met her 29 years ago and how long have you been married?

Dan Gasby: We've been married 23 years this December 23rd.

George Vradenburg: You say you saw these little signs, mood changes, forgetting words, concerned about the relationship going south, how long did it take you to get from seeing the signs until you actually got a diagnosis of a disease?

Dan Gasby: That's an interesting question, George. Now when you look back you realize it was longer than it actually was because it's like a snowstorm or a hurricane, you know when it's over but when did it first start? It started with a few flicks or a few drops of rain. Now when I look back, although her diagnosis was 2013, I would have to say it was even more like, even early as the last part of '10 or '11 that I actually started to see these things that said, "Wow, what's going on?" I call it the wtf period, because that's what it is. You keep asking yourself, "Is it me? Is it me? Is it me?" because when you're so close to a person, when you're like the other side of a coin and you can look across the room and talk to them with your eyes and they can communicate to you with their eyes or body language, and all of a sudden you're like the train tracks where so long as they're parallel the train is fine, but if it's a 10th or 100th of an inch, the further you go the more you see it's different and ultimately the train will derail. That's the same thing that started to happen with our relationship.

George Vradenburg: Did you try to get a diagnosis and did you have any particular experience with the medical professions ability to detect what you were seeing and to get a diagnosis?

Dan Gasby: Absolutely. First thing, you have to be able to say to yourself, "If something's not right, you have to go or change doctors." It could be for a variety of reasons. In one case, she was treated more like a lab rat than as a person and there was just this, "I think she has this and we need to keep her on anti-depressants." He was giving her so many different anti-depressants and then he went to these patches on her back that it almost looked like you were playing some sort of mad game that you couldn't believe. It almost looked like, I guess you could call it a Picasso painting. I said, "This ain't right. This is not right." Then we made a call, talked to a few people and then had tests done. They came back and said, "There's definitely something here. There is some significant loss of memory, significant not understanding certain things with regard to executive function." That's when we went to Mt. Sinai and that's when we decided to get the amyloid plaque test and that showed conclusively that she had plaque on her brain.

George: Vradenburg: A person online has asked again for the name of the book, which we can give or you can recite it, Dan.

Dan Gasby: Before I Forget: Love, Hope, Help and Acceptance in Our Fight Against Alzheimer's.

George Vradenburg: There's a person who I think I'd like to have ask a question now because it goes to this question of the emotional, unsettling feeling about whether there's something the matter in the relationship or otherwise. This is a question from Rich Gardner from California. Rich, would you go ahead and ask your question now?

Question: Absolutely. First of all, Mr. Gasby, thanks for your advocacy. I lost my wife Debbie at 59 to this cruel disease and one of the hardest things for me was to research it, know the 7 stages. I read in People magazine that you said she's in stage 5. To me it was gut wrenching when she hit stage 6, do you feel that way too, or do you have a different attitude about it?

Dan Gasby: Rich, it's gut wrenching every day. It's gut wrenching. I can share with you, in the last week, I almost lost her twice where she got out of the car in the middle of midtown as recently as yesterday and I had to, basically, we were stuck in traffic and she got out and because the way the traffic was going and she just said she wanted to take a walk. And when I looked around - she's like a gazelle, she disappeared. It's gut wrenching every day, Rich, because I have to be realistic and I know it's sort of like the Titanic, I know where it's going, but I'm going to buy as much time as I can. We're on this call to try to make a difference and maybe find a new trial or something that's going to allay it, but we know where we are. It's very gut wrenching, yes.

George Vradenburg: Let me ask some questions about caregiving. Normally we think of a caregiver as a woman and not a man. What has your experience been like as a caregiver and how might it have been different as a man than as a woman?

Dan Gasby: Let me just say this and I think it's extremely important. I now understand what a single parent is. I understand when you cook, clean, have to train or be the discipline ... and you have all of these other things working around you or working to you or through you, and at the same time, at that point when you're dealing with a person who has Alzheimer's in the 2nd stage or the 4th or 5th stage, you become a parent. You become a mother figure in many respects. You have to be the nurturer. You know that you can't negotiate. There is no negotiating Alzheimer's to the person who has it. Then depending upon how you're built intellectually and psychologically, it's very difficult, but you have to understand. I have to constantly tell myself, when I get upset or when I get frustrated, I have to say, "It's the disease."

When she tells me something that makes absolutely no sense whatsoever I have to take a moment or she tells me she doesn't want to be with the caregiver or the caregiver is a bad person, or the caregiver has stolen something or she's taken something. You subterfuge, you have to change directions, you have to do things that locks that person in on one thing so that they forget what they're talking about that's bothering them. It's tough. It's almost like chewing glass at times, but you understand you have to do it. It's almost like riding in plane going through turbulence, but you have to say, "Put the seat belt on and he's going to find clearer air. He's going to find smooth air, we've just got to ride through these bumps." That's what I have to say to myself at times because I'm a human being and I have feelings. No one likes to be told that they hate you. No one likes to see a look in an eye that's primordial and you can see that anger and you know it may only last 15 minutes or 15 seconds, but you feel it because you're experiencing it visually and you're hearing it.

I do understand that I have to remove myself and at times get clinical to get through and then it changes 15 minutes later or the next morning, but it's difficult. That's why it's so important. That's why we're doing this. That's why we're going to get the monies, and the resources from the government, get trials going, get more people participating. I don't want somebody 20 years from now to go through what I'm going through in 2036, going through the same thing we're going through in 2016.

George Vradenburg: I know that you have been out there as has B. in urging people to sign up for the Brain Health Registry, which is a website that collects information to help people get more information about clinical trials. Could you just explain your experience with Brain Health Registry and why you're promoting it?

Dan Gasby: Yeah, the Brain Health Registry is an opportunity. Here's the thing, medicines operate differently on men and women, they operate differently on different races of people by virtue of our genes, our genetics, and if you don't have a representative sample pool of a particular ethnic group, then you have the opportunity not to have drugs that could possibly work maybe for one group and not another. What scares me is I use that term 2036, because I know we're working for 2020 to make giant strides, but what scares the bejeezus out of me is that we don't have enough African-American and Latino and people of color in these drug trials and that the drugs that are working, work for one particular group and not these groups. Twenty years from now, we'll be talking about this being something mitigated or even eradicated, but in certain populations, let's just say the African-American population, because we don't have enough people participating, we're still finding that there's an increase in Alzheimer's. That would be tragic.

That means that another generation, it would be to 2050 or 2060, that there are enough people to figure this out. I want to shorten the time that it takes for people to get involved with this and to make a difference and that's why I urge people to get involved with the Brain Health Registry. It's easy to do, it's online, you sign up.

The other thing is, this is about America. We've had a historic problem with African-American's not trusting the system and particularly because of Tuskegee and because of sterilizations or the one that I've heard just recently is that if a white person is on a gurney and a black person is on a gurney and they're sick or hurt and they need a transplant, you know who's going to be harvested.

These things are not going to happen. We talk about some of this stuff in the book with regard to Henrietta Lack and how things have happened in the past, but there are lots of safe guards now to prevent those types of situations from happening and we have to overcome those things because what we're doing by participating is giving our children and our children's children and maybe even our children's children's children an opportunity to not have this disease.

George Vradenburg: Dan, what you say is so critically important. We're told so often by people in industry that a pacing element and the speed with which they can get innovative medicines to market, a pacing element in whether or not they're prepared to invest in new drugs is the sluggish, slow, expensive character of clinical trials. You have hit the nail on the head in terms of a specific thing that individuals can do to accelerate innovative medicines for all the populations of the United States.

We like to point out that by 2050, a majority of people in the United States are going to be African-American or Latino and the health of America is going to be the health that we can drive into our African-American and Latino community, so you're absolutely right. In fact, if anyone on the phone would like to join this fight to stop Alzheimer's by getting more information on the Brain Health Registry and sign up, just press 1 now. We'll record it and we'll send you detailed information on how to sign up.

Let me come back a second Dan, to caregiving. What kind of care arrangements do you have now? What kind of care arrangements have you been thinking about in the months and years ahead?

Dan Gasby: We now have a lady who is here anywhere from 3-5 times a week depending on need because we are, right now, traveling so much and doing things together, but I see a day coming where we're going to need more critical care. We work with a group here in Long Island, between the Alzheimer's Association and the Alzheimer's Disease Resource Center, they provide you with information about various long term care and counseling that you need because you can't do this alone. We do have a caregiver. The thing is time and treasure. It's a 6 figure endeavor when you start to add up between what it costs for adequate care or what it costs in terms of giving up your own resources and still having someone there. Between that, and my daughter is now pitching in, in a great way and we have a great caregiver who at times my wife loves and at times she can't stand, but I understand it now.

That's why you have to be clinical, but we have care 8-10 hours a day because the other thing is, quite honestly, I've been doing it myself. Maybe it's part of that historic situation that African-Americans, believing you can pull the cart all by yourself or I've got big shoulders, but you know what, my shoulders, I see, are not that big. You have to get away. You have to refresh. You have to reboot yourself to be able to handle it day in, day out, the 24/7 aspects of this disease. Alzheimer's doesn't negotiate. It doesn't negotiate. It's like fire, it's pure.

George Vradenburg: When you travel, do you travel with a caregiver or are you the full time caregiver when you travel together?

Dan Gasby: It depends. Normally like this past weekend I traveled by myself and then we set up arrangements to have people come with her or friends who help, but we have done it with a caregiver too. The great thing about B. is that we do know so many people that love her and that they want to be around her. I have traveled with a caregiver and when we go on vacation, for me to have a vacation too, I'm going to have to travel with a caregiver.

George Vradenburg: What do you do to avoid burn out? You say you need to escape from time to time simply to reboot, how do you manage that?

Dan Gasby: I work out. I read when I can. It's interesting, I'm like between Oscar and Felix, I'm the one who's very neat, and we both were, but because my wife now has this difficulty in making executive decisions and seeing things, the house gets to be a mess, I get up at night and I honestly go around and I put things away that she's left or clean up things that are messy where our house used to look like, right or wrong, like a museum in perfect order because she is a lifestyle person. I get a great sense of enjoyment just making sure that the house is as best I can when we wake up the next morning. I work out 6 days a week, that's my big thing. I read. I go for walks with the dog, with her or with the caregiver being here, I'll go out and walk or take the dog out or now in this case we have both dogs, take the dogs out and just get away. I meditate. I try to do at least 15 minutes a day, it's been a big help.

George Vradenburg: We have a question and comment here from Joyce Simons, I hope that's correctly pronounced Joyce, from New York City. Excuse me, from New City, New York. Joyce, would you like to ask your question?

Question: Yes, hello. I'm an African-American woman who's living with this disease and I've been an advocate for awhile. I was diagnosed a couple of years ago. I do understand the difficult that you have with dealing with African-Americans who are just getting information. I know that you do outreach to everyone, but have you specifically done outreach within the African-American community and if someone called you and wanted to have you do something within a group, a large group, would you be willing or able to do that?

Dan Gasby: One of the things by working with African Americans Against Alzheimer's is one of the ways that I've been able to get the word out. I'm not opposed to it. Please, if you send the information in, we can see how we can make some arrangements.

George Vradenburg: At the end of this call, Joyce, I would ask you simply to stay on the line briefly and leave us a message and we'll let you know how to get in touch with us with any suggestions. Quite clearly Dan, has a very, very crowded lengthy schedule on top of his caregiving responsibilities. I have no assurances here, but please, we'll be delighted to pass on suggestions that you might have.

We do have a question here from Michael Ellenbogen from Philadelphia. Michael, do you want to make a comment?

Question: Sure. This is in reference to the Brain Health Registry. I think it's really a great program that they have out there. I believe, and I don't know if you can influence this, since it sounds like you're somehow a part of this now, I would like to see them give back a little bit to the people who are living with the disease who are helping out. What I mean by that is, we're doing all these tests that tell them about our cognition status. Why can they not share that information back with us as they see us decrease, to do some sort of comparison with the test we took, let's say 6 months ago, to the one that we take now and just give us that feedback if we ask for it? It should be able to be done very easily if somebody automates that.

George Vradenburg: That's an interesting question, Dan, as to whether or not that is a useful addition to the Brain Health Registry to make people aware of whether they're declining or not declining with respect to their cognitive abilities.

Dan Gasby: I think that's something we certainly can talk to the folks there and get some sort of feedback and find out if and why, don't you?

George Vradenburg: I think there's no question we can ask them. I'm really curious though, if earlier in the stage of this disease, if B. had gone on the Brain Health Registry whether it would be useful information to her or to you, to know whether she was declining, the rate at which she was declining, or whether you see that in your daily life anyway. I just am curious as to how as a user of the Brain Health Registry, you might see that additional information?

Dan Gasby: The metrics, you see it anecdotally, you see it empirically through what is said or not done or how things are analyzed based on everyday situations. When you're real close sometimes you don't realize the progression, but I think that's something we can definitely talk to BHR, the Brain Health Registry folks, and find out what their thoughts are and if that is something that could be articulated.

George Vradenburg: We have a question online here from Cheryl Du Lac who asked, "Does faith play a role in your ability to be a good caregiver?"

Dan Gasby: Oh, definitely. It doesn't make a difference what religion you are. I'm a Christian, but I think you have to seek a higher power, a spirituality, even just understanding that the belief in something greater than yourself that gives you the strength to go on and that you don't find things to be totally meaningless. Basically, I believe through my teachings that each person has a responsibility to try to make it better for others and that comes from my Christian teachings. I am not important, others and making it better in the world is just something that I totally believe in. The doctors say, "Do no harm." I believe, try to do some good, don't just be here as a taker. Be here as someone as who's trying to make things better for the future. Let me tell you, I've cursed God out and asked, "Why did you do this to this woman?" There are so many people out there who by virtue of just their lack of concern or care or their evilness that didn't get this, and then I'd ask for forgiveness. Yes, faith is very important, it keeps me grounded.

George Vradenburg: Yeah. You released your book on Martin Luther King Day and you've called this a 21st century civil rights issue. I am interested in why you characterize it as a civil rights issue, and why you particularly emphasize that by releasing the book on Martin Luther King Day.

Dan Gasby: As you know all too well George, to make this situation better it's a mission, from out of the shadows, to awareness, to a movement. When you look at 2 out of 3 people who have Alzheimer's are women, if you're a person of color, if you're black you're 2 to almost 3 times more likely to have Alzheimer's. If you think about the cost of care, people who don't have a lot have to give up so much in terms of their own time, not to mention their treasure, the money. It could literally set a family into poverty or cause them to have to sell their homes. Their dreams are put on hold because they have that responsibility as caring family members to do it.

I want this to be a movement because it's impacting 5 million people right now and there are 15 million caregivers, based on the notion that there's 3 caregivers for ever person stricken with this disease. We've got to make a difference and the cost is so great that when you look at that, you say to yourself: We can build roads. We can go to the moon. We can split atoms, but the top of our head, the thing that gives us dignity, the thing that gives us culture, the thing that gives us a sense of where we're going in the future, there needs to be more money spent. The people who are most impacted by it are the people who have the least amount of impact traditionally in the country. Women make 77% of what a man makes, that's not right, and two-thirds of Alzheimer's sufferers are women, so it's a woman's issue. It's an African-American issue, because it could set back the gains that we made from the 60s until now in terms of the number of people. It's a tsunami in the black community, everybody knows somebody with it or in their family. You sit in the room and you ask people, "Raise your hand if somebody has it in your family," hands go up. Raise it if somebody that is your next door neighbor or friend, you basically find everybody knows somebody, so it's the 800 pound gorilla that's wrecking the whole house, so that's why we called it a 21st century civil rights issue. It's a matter of human dignity and our country has the resources. They spent $6 billion on Ebola and we spend $1/2 a billion a year. Basically they spent in one year on Ebola what they've spent for over a decade for funding. It's not that we don't have people to do this. We have the brightest people in the world right in this country, but they need the resources to spend on RND. The government needs to be behind this in conjunction with private industry.

George Vradenburg: You dedicated your book "to the men and women of the U.S. Congress who have the power to help spare future generations from the ravages of Alzheimer's and to all who will be helped by them". You seem to have chosen a dedication, aspirationally..

Dan Gasby: George, let me say this. I believe in America. Democrat, Republican, Progressive, Socialist, Conservative, far right, Evangelical, we're all Americans and the congress does do great things, even though they have a low opinion by many people, we got to make them do what they need to do. They can help turn this around. They helped create the internet. I'm glad I was born in this time, in this country. I could be in a lot worse shape if I was born in Syria or somewhere in other parts of the world. And to have this opportunity to come out of Brooklyn, out of Bed-Stuy out of a tough neighborhood and to be able to sit here because my wife has been dealt a tough hand. Now I'm going to try to make that hand better for her, but more importantly for other people. The only way to do that is you got to vote and you've got to send notes and you've got to be ambassadors and you've got to motivate people to make a difference. That's why I dedicated it to the United States Congress.

George Vradenburg: Your message I think is getting through. Congress did increase by 60%, the investment in Alzheimer's disease in December with the respect to this fiscal year and NIH has recommended a similar increase for fiscal '17 budgets, which President Obama will propose next week and which will be entertained by Congress in the spring. Your message is coming at the right time, in a time when I think people have begun to open their ears and that has not been the case for a very long time.

You mentioned before, you're concerned about 2036, or 2040, or 2050 and '60. My wife and I founded UsAgainstAlzheimer's because we recognize that 25 years after her mother had been diagnosed with Alzheimer's, nothing had changed. Her mother diagnosed in '85, and now it's 2010 when we founded this organization, nothing had changed.

People are beginning to open their ears. You're opening a lot of people's ears. B. Smith is opening a lot of ears, her fame, her beauty, her kindness is causing people to say, "Look, if they're willing to talk about it, if they're willing to be courageous enough to bring it out of the shadows, than damn it, I ought to be able to do that. I ought to be able to talk about it," and it is beginning to have an impact. I applaud you for that. That's not the end of the conversation, but I'm just saying, I applaud you for what you just said and what you're doing.

Let me ask, this is a question that came in before the call. On Good Day New York, you mentioned a test, although it's expensive, that can tell you exactly what's going on. Kristen Graney from White Plains asked, "Can you tell us what that test is, how to find it ..."

Dan Gasby: Yeah, it takes about an hour. What they do is you go into the hospital and they put a radioactive isotope into your veins and it runs through your entire brain and what it does is it shows where the plaque is built up. When they take the pictures and they can look at it 3 dimensionally or 4 dimensionally, they can see, it almost looks like whiteout on a paper where the plaque is. The plaque and tau tangles what kill the neurons in the brain, they can tell. It's not 100% certain because some people have plaque and they don't, but it's well over 90% that this type of test gives you the information. The thing is, this plaque buildup doesn't happen overnight, you can begin to see it 10, 12, even 20 years before the impact of Alzheimer's takes hold. Just think of it this way. If you were able to see that that was starting to happen in 2016, maybe through diet, exercise, taking vitamin E, doing different things you could slow that down and over the next 5, 8, whatever years, as technology advances and medicine advances you may be one of those people that could actually reverse it because we're spending more money or eliminate it.

I always make the analogy, if you think about 30 years ago what a telephone looked like, a mobile telephone, it was on a backpack and then it became a milk carton with a straw, and now it's not just a telephone it's everything. It's a computer, it's got a hundred thousand times more computation power than the original computers do right in your hand. We want to buy time. This plaque, if you can see it now beginning to develop, you could now understand that I've got to get going. I've got to eat better. I've got to exercise more. I've got to do things that are going to help me, hopefully slow this process down so that I can also be an advocate for more money being spent and for technology to catch up. I call it buying time and creating hope.

George Vradenburg: You are so right. And your body can build a greater capacity to resist heart disease or other kinds of diseases that can also build capacity in your brain to resist disease, not to cure it, not to stop it, but to resist it.

Let me ask about technology. You mentioned cell phones, are there other technology aids that you're finding useful whether it's devices that you might attach somewhere to B. Smith on her shoes or elsewhere for her wandering, cell phone, monitoring technology?

Dan Gasby: Absolutely. We have a locket that she wears and we have a GPS wristband that we use. What happens is you see things and then they become all of a sudden overly apparent. Things happen, like in the city, I know I have to have the band. She won't leave out of Sag Harbor, or she won't go out here, but in the city she takes off. She'll just take off and maybe it's because she's always been a free spirit and she loves walking and just watching things, but she'll just take off like a pigeon flying out of the coop. It's very important to have the GPS tracking device. Those are some of the technological advances that you have to have when you're caring for someone so that you can track them.

George Vradenburg: Let me ask, this is a delicate question. I've got two delicate questions here. First, how has your love for B. changed as a result of this experience?

Dan Gasby: Yeah, that's a delicate one, but look it's not the same. It's not the same and the reason it isn't is because there's a lot of energy expended in terms of being a caregiver. There's more holding and more, let's just say, sharing of each other's emotional space, but it takes its toll. When you love someone you don't love them just for the physicality of sex, you love them for their being, for their very essence. You learn to appreciate the person in new and in some cases, I think, more profound ways and then you really understand that love is not just a sex act, it's really, quite honestly, it's the care that you have for that person totally. I always say to young people, because we used to be in the restaurant business - I would say, "Look, you got to like who you love, not love what you like." I practice what I preach, but no, it does change there's no question about that. You can't expect someone with Alzheimer's necessarily to initiate. You can't expect someone to go through all of the things that emotions bring and the tension that brings with loving someone and everything, but if you love them you understand that just because that's not there doesn't mean that there's a whole wealth of feelings and sense of enjoyment that you have with the person.

George Vradenburg: I think that's very profound of a notion that your love changes, but may deepen in certain respects and get frustrated in others.

Dan Gasby: George, you know me. You know me well enough, I'm going to tell you the truth. What I try to tell people, living with Alzheimer's is not like a sitcom and at the end of 30 minutes we resolve everything.

George Vradenburg: One last question and if this is one that you don't want to answer, please let me know. Have you thought about end of life choices, preferences?

Dan Gasby: We both have wills. As a matter of fact, I'll tell you something that I've probably only told a few people. Long before Barbara and I had Alzheimer's as something that's staring us in the face, we were laying in bed one night and I said to her, "How do you want to be remembered?" I said, "I know how I want to be remembered." She said to me, "I want to be remembered as a person who tried to make a difference and tried to make things better." I said to her, "I want to be remembered as someone whose always had plans on the table, always trying to do something, not just about myself, but do something." We've been big boys and big girls about that. No one gets out of this alive. We have our trusts, we have our wills, we have all of those things. I can tell you this, in my heart of hearts, I wish I had it and not her. I honestly do. But whatever we do, I'm going to take care of her. I'm in this for the long haul and I'm going to take care of her until I just simply can't do it and the only way I simply can't in some respect is if God takes me first.

George Vradenburg: Dan, you and B., both of you are going to be remembered for the changes that you've made, the awareness that you've brought, and the love that you've expressed toward each other, and you're doing precisely, and being remembered precisely or being known, you're not being remembered yet, you're known for doing precisely what she would like to be known for having done. She is going to be remembered as one of the great advocates and you are now becoming her voice in her advocacy as well as yours. The difference you're making is palpable, real, and dramatic. We very much thank you for your candor, and your advocacy, and your love. You have shared with us so much and we so deeply appreciate your being on the call today.

Dan Gasby: George, can I just say one last thing?

George Vradenburg: Sure.

Dan Gasby: I just want to thank you, first of all, for what you've done. As my old man used to say, "Everything in life is simple, it's just not easy." I know what you and your wife have done and how you've spearheaded this thing. I want to thank you for allowing me to share what we're doing and I want to thank everyone out there who's listening and I ask one thing of you, send a note to your local and your federal representatives talking about more funding. This is not a waste of money, this is pay a little now so that we don't have to pay so much more later. That's all I ask, send a note, email, whatever because they operate on the squeaky wheel basis. We need to have more ambassadors out there to make a difference. When you do that, because you'll know somebody who has Alzheimer's, if it's not in your immediate family, and you'll feel good because you'll know you're part of the solution, not part of the problem.

George Vradenburg: Thank you for that, Dan and for all of you out there please just go to UsAgainstAlzheimers.org, sign up and we will send you regular updates on exactly how to do what Dan just described and automatically fill in the information that you need in order to write your particular congressperson and your particular senators. I know that if all of us get together, if we do what Dan has urged us to do, which is to talk about the disease, to act on it by talking to our political representatives we'll get the funding we need in order to get this disease stopped. This is America, we solve big problems and we do it a lot in this country, we can do this one too. Dan Gasby is one of the nation's foremost advocates for exactly how to make that happen.

For everyone on the line, thank you for participating today. We'll have a transcript and recording on our website in about a week. If you'd like to leave us a message, particularly Joyce, if you'd like to leave us a message, please stay on the line, with a question or comment. We're particularly interested in what you would like to discuss on future calls or how you might, yourself, get involved in the movement that Dan has talked about today.

Thank you for joining us today. Have a good afternoon. Dan Gasby, thank you and thank B. Smith. Thank B. For what you're doing.

Dan Gasby: I definitely will.

George Vradenburg: Take care. Goodbye.