

## Alzheimer's Talks Transcript

July 25, 2012

### Rediscovering My Father: Sargent Shriver, a conversation with Mark Shriver

George Vradenburg: Welcome to Alzheimer Talks, a conversation with Mark Shriver about his new book, **A Good Man: Rediscovering My Father, Sargeant Shriver**. My name is George Vradenburg. I am Chairman and Co-founder of [USAgainstAlzheimer's](http://USAgainstAlzheimer's), an element of an organization, all of whose members have been affected by this atrocious and terrible disease. Thank you for joining us. This is the fourth in a teleconference series by USAgainstAlzheimer's and today's call is sponsored by the Zickler Family Foundation.

Just a couple of words by the way of introduction of Mark Shriver. He's currently the Senior Vice President of Save The Children, US Programs. He joined Save The Children in 2003 and developed the Deserve a Childhood development literacy and health Programs for children living in impoverished rural areas of the United States. Today, those programs benefits more that 70,000 Children in nearly 200 locations. Mark was a member of the Maryland House of Delegates from 1994 to 2002. His memoir about his father, **A Good Man: Rediscovering My Father, Sargeant Shriver** was published in June.

If you have a question for Mark during the call, please press star 3 on your phone. By pressing star 3, you will be placed into the question queue. Please have your question ready to share briefly with a member of our staff and then they and we will try to get you on the air with Mark as soon as possible when we open it up for questions.

Mark, thank you so much for joining us today and having finished your book just this week. I must say, it's an extraordinary story, very personal, very touching and very insightful. And as my wife said in her review of your book, you're too hard on yourself. You're a second good man in this family. So Mark, some opening thoughts and then we're going to spend most of the rest of this hour on questions from me and from the crowd that's on the phone.

Mark Shriver: Thank you very much, George. I appreciate that kind introduction and the review that Trish wrote of the book was beautiful. She was always my favorite Vradenburg and she still is, so thank you. I don't know if she's listening in but I want to thank her as well and I'm honored to be the fourth participant in this Alzheimer's Talk series and I want to thank the Zickler Family Foundation as well for their support.

I thought I would just say for a couple of minutes about why I wrote the book and it obviously does touch on Alzheimer's. A big section of the book is on Alzheimer's but I really wrote it after my dad died because so many people came up to me and told me that he was a good man and at first I thought that that phrase was just nice thing to say to someone who had lost their father and you know 18 months earlier, had lost their mom but I realized that through the repetition of that phrase that the people meant something different and I

wanted to dig in and find out what a good man meant. It was different then being called a great man or a great woman as so many people in Washington often refer to themselves and sometimes other people refer to them as great men or great women and Dad had a lot of folks saying that because of his work in creating the Peace Corp, his efforts to create Head start and Job Core, Foster Grandparents, Vista, Legal services for the poor and President Johnson's War on Poverty and also his work with my mom, spreading Special Olympics all around the world. But I think what made him unique was the fact that he was a good man and that he was happily married to my mom for 56 years. That he raised 5 kids, all of whom loved him. That he went to mass on a daily basis. That he had countless friends like the 2 waitresses from his favorite restaurant that waited in the wake line for you know, half an hour to say your father was a good man and they turned around and walked out of the church. The guy from the US Air Counter at National Airport who said the exact same thing, who told me that some of his happiest memories was working with my dad and getting through the security line and just said, you know your father was a good man. The guy who collected trash in our neighborhood got out of his trash truck, pulled to the side and got out and walked up the driveway to tell me the day after my dad died that he was a good man. And I wanted to figure out as a son trying to balance raising 3 young kids, dealing with parents who are aging and in-laws who are aging and suffering from Alzheimer's, how he balanced his family and his friends and his faith and his commitment to the community. In my dad's case, commitment to the world and how he did it so joyfully. That's really what the book is about. It's about a quest of a son to figure out how to be a better father, how to be a better friend, how to be a better husband and how to do it with joy.

Dad did a lot of things on a lot of different stages but you know, when my college friends had come over to visit him when we were in school and after we got out of college, he'd have a couple of vodka tonics and break out the cigars after dinner and tell stories and laugh and be up the next morning at 6:30 or 7:00 going to mass. And obviously, a big part of the latter part of his life was dealing with Alzheimer's which we had kind of a sense of in the late 90's but he was still running around the world and doing a great job giving speeches. He was forgetting things and getting confused at times but he still had the ability amazingly to get up and give a speech. He made a lot of it off note cards but he didn't get confused and he would do it exceedingly well and he was still energizing people. But when my mom was in the hospital in late 2000, we finally brought him over to see a doctor at Hopkins who diagnosed him in the early stages of actually, early to mid stages of Alzheimer's and how we dealt with that and part of the book talks about how, I guess, essentially, I denied it. You know, kind of rationalized his behavior as really nothing more than old age and you know he was at that point in his mid 80's. You know, 83, 84, 85 before he was officially diagnosed with Alzheimer's. And at that point of time, there wasn't a whole lot of medicine, I know there's not today, to figure out how to deal with the issue of Alzheimer's, the disease of Alzheimer's. So he went on Aricept and he still went to events that George and Trish ran and not only Alzheimer's but other events associated with the family from Special Olympics to my brother's work at Best Buddies to events that I had for Save The Children in Washington DC.

But the story, the book, really does deal with his gradual decline. Having to find help that are called caregivers, but really believing that caregiving is an inadequate term, that it's really love-giving. That you really have to essentially be willing to give unconditional love to the person that's suffering from Alzheimer's, your loved one because care isn't really sufficient. That it's a level on a gut level of love that you have to give that can zap you of your energy. But also I think that the book does deal with a number of experiences that I had with dad even

when he was in the mid to latter stages of Alzheimer's in which he had moments of clarity and how he showed who he really was.

And as I said to George, a couple of weeks ago, the essence that the book is broken down into the 3 principles that drove my dad's life and they were his faith in God and that faith demanded the acts of hope and acts of love and that faith, though he was a Catholic was not exclusionary. It was an inclusionary faith in which he reached out to Jews and Protestants and Muslims. People of all faiths to try to work on doing as he called it Our Father's business and that phrase really shocked me when I read in the speech that he'd given in the mid 60's when he worked for the federal government. He was calling upon all people of faith, people who wanted to feed the hungry, clothe the naked and shelter the homeless to do our Father's business and that's really the work of the spirit, the work of God. However you get that point, and that inclusionary faith demanded acts of hope and love and when Alzheimer's stripped him in his later years of his memory, and strip him of the idea that there was a future or even a tomorrow. What was left at his core was his joy and his love and that's what the book is about.

How did this guy not only balance faith and family and friends and commitment to work but at the very essence of who he was when he didn't really know that I was his son and had some irritating habits like blowing his nose constantly whether it was in a napkin or a tissue or not. Once I went in to church and I told this in the book... taking our kids into mass and going, God, he's going to get my kids sick. He's blowing his nose. I'm going to get a cold. This is going to last a month. I had little kids, a 5-year-old, a 10-year-old and a 12-year-old at that point. It's going to be a disaster. Three minutes into it, he put his hand in my lap and then put his head on my shoulder, a minute later and then two minutes after that, just turned to me and said, I love you and, did he know that I was his son? Did he know that his grandchildren were right next to him? I don't think so. But he knew that someone there was caring for him and loved him and that was what he gave back and there's moments of insights like that that really whether I got a cold or not was irrelevant whether my kids were sick is ultimately irrelevant but what was important was that unconditional love that he was giving me and really everyone around him that made a profound impact on people including obviously his son and children.

So there are moments of great sadness in the book because Alzheimer's obviously is a brutal disease but there are also moments of great joy in the telling of Alzheimer's because there are you know, in the midst of that pain and suffering, there are moments of insight and clarity, at least that's what I got from my dad and that's what I got from dealing with Alzheimer's.

So George, I can pause. I've talked more than 5 minutes. I don't know if you want me to touch on anything more about the book, but it's really built on those principles of faith, hope and love and how I came to understand the work that he did in the Peace Corp and Head Start and Legal Services and really came to know, not from a biographical perspective, not as a historical figure but as a father. And how he still despite all of those different pulls on his time, was such a loving husband and a good friend, not just to presidents and cardinals and big shots but when their lights were turned off, he was, you know, the guys behind the camera, the person at the gas station, the person at the restaurant, the person at the airline counter, all considered him to be a friend and a good man and that's really what I try to dig in and understand and how he did it during his battle with Alzheimer's.

George Vradenburg: You tell that story and the story of your father and his character and his faith and love extraordinarily well. I was struck. I'll ask one question then we'll start asking questions from our listeners. At one point, given his faith and his love, these are attributes of the mind and the soul which we think are resonant in the brain but you at one point were curious about what he was thinking about this and you told sort of a conversation in the book about asking him how it made him feel that he was losing his mind. Could you describe that a little bit more and his response?

Mark Shriver: Yeah. I mean essentially, when dad was driving over to visit us because my folks lived a couple of miles away and I was in charge of my dad's medical and financial issues and my mom's and I was driving them over and we stopped at a red light and on some unknown, exact corner and he looked over and I looked over and it looked like he was in a moment of clarity and I said to him, Dad, of all the questions I could ask, I don't know. I just ended up just saying to him, "Dad, you're losing your mind. How does that make you feel?" and without missing a beat, he said "I'm doing the best I can with what God has given me" and I think that that was his approach to life.

I think he did the best he could with what had God had given him when his family survived the depression and lost all their money and declared bankruptcy. I think that he was doing the best he could with what God had given him when he was surviving a brutal battle in World War 2 and he did it in joyful moments by creating the Peace Corp. He also did it in a moment of sadness like organizing President Kennedy's funeral in which Jackie Kennedy asked him to do that from Friday afternoon to the funeral on Monday and it's an amazing accomplishment when you put it, when you really step back and figure out that he had 3 young kids at home and his wife was pregnant with me, you know, 6 or 7 months and he somehow pulled that all together and did it with such grace and such meaning to not only Americans but to the world. And I think that that's what sustained him when his final cross, if you will, was the bearing of Alzheimer's. And I don't know enough whether love and forgiveness is a part of the brain or part of the soul. I guess that it was just the essence of who he was. I think he always tried to do the best he could with the gifts that were given to him and the opportunities, and I think that's what made him a good man as well.

He saw every moment as a gift from God, as corny as that sounds, and it gave him incredible energy because every moment was a gift but it also paradoxically slowed him down because he realized that every moment was a gift and he needed to be in the moment and that's what Alzheimer's did to him. It stripped him of the past. It stripped him of his future. It left him in the moment because he didn't know that he created the Peace Corp. He didn't know that tomorrow was Thursday. He just knew he had you and that was a really powerful message for me to figure out that here was a guy that was living in the moment, had lived his whole life in the moment, and when he was struggling with Alzheimer's, was teaching me again to live in the moment. As brutal as it was at times, there were also insights like that. At least they were there for me.

George Vradenburg: We have a question that was submitted by Virginia Moore-Bell from Montgomery, Alabama before the call and I think, Virginia, you are on the call. We would love to have you ask a question if you are available to be unmuted. Good. Would you please press star 3 on your phone, Virginia, and we'll have you ask your question? So in the meantime, let me have Annette Guidry who has submitted a question. Annette, could we have Anette ask her question of Mark Shriver? Annette? Hello. Okay. Meryl Comer of the Geoffrey Beene Foundation has got a question and Meryl, could we have your question please?

Question: Thank you, Mark, for writing this book, for sharing your dad's story. I was honored to receive the Profiles in Dignity award. My question to you is, there is such stigma that surrounds this disease. That it is a very heroic act in the decision to go public and the issue of coming out and protecting a loved one's dignity at the same time is a complicated conversation in families. Can you discuss what went on and why you made the decision to go public?

Mark Shriver: You mean with dad when he got the disease and/or excuse me, when he was diagnosed in early 2000 or the writing of the book or both?

Question: Well both. Yes.

Mark Shriver: I guess, I might jump around here but Maria had been working, you know, before I wrote this book. Maria, my sister, has done a lot of work on Alzheimer's, an HBO special on Alzheimer's. I guess originally, you know every family has its own issues that they deal with and the last time I checked, there's no family that's perfect. You know, somebody said to me wow this book took a lot of courage to write and when I thought about it, I don't really think it did because I think everybody and every family has their own dynamics and their own issues at play. You know I wrote in there that I struggled in elementary school as a fat kid. You know, somebody's got a fat kid, somebody's a geek, somebody's part of the cool group, somebody's not. If you are in the cool group, at some point you're not. You know, so we've got to be honest, that were all struggling with this stuff and I think you know within our family and for dad he knew his memory wasn't as good as it was. My mother knew it so why hide it. He was still going around the country and the world giving speeches. He wasn't doing it as well as he did 25 years earlier but we were honest about it and I can't tell you the number of people that's suffering... have a loved one suffering from Alzheimer's. The guy I had lunch with yesterday who I worked with at Save The Children, his father is in the early stages of it and how he's dealing with it. Rode in the elevator today with somebody today from the office who read the book and father and mother are dealing with Alzheimer's.

So I don't want to be cavalier about it. I know it's tough, you know, a conversation to have but I don't think anybody, any family, isn't struggling with something. And if you're struggling with Alzheimer's and need help, that's part of the human condition. I mean my father really believed that we were in this crazy thing called life together that you have this strong, individualist streak in American history but that ultimately no one does anything without the help of friends and the community, the greater community while relying on each other. So when he was suffering from Alzheimer's, I think as a family I don't recall having distinct conversations about it. It was, Dads got Alzheimer's how can we help him as best as we can. You know he was in a public role. He's going to cut back on some of those speeches and we're going to tell people why. It's nothing to be ashamed about. It's part of life and I think writing the story was the same thing. For me he was a guy that that people resonated with as a good man that suffered a brutal disease and how he dealt with it maybe could help some people. Definitely sitting down and writing it I guess from the selfish perspective was helpful to me. So I don't know if it was heroic. I think it was more, you know, something that I needed to put down in writing and I think it's helpful to other people. So that's why we did it. You know everybody's got... if somebody doesn't have Alzheimer's, you know, a childhood developmental disabilities or kids who are dealing with alcohol issues or something like that. You know we all got it.

I think that's one of the great things that I felt on the book is people have come up and said, I thought originally this is going to be a book about some kid in a famous family and a famous father but really it's almost nothing to do with that. It's about a father and a son and trying to figure out how to live life better and to deal with the great moments of joy but also the moments of sadness and Alzheimer's is part of the sadness tinged with joy. I don't know if that answers your question.

Question: Thank you

George Vradenburg: I'm going to ask Susan Alexander to press star 3 and we will allow you, Susan, to ask your question. In the meantime, I want to go back to a question submitted by Virginia Moore-Bell. This was her comment. "It has been told to me by many family members that one of the most devastating things about dealing with Alzheimer's disease is watching their loved ones slowly change right before their eyes, unable to communicate with words or recognize those they loved the most. What are your suggestions for the caregivers who are experiencing these signs of pain? How do the family members who are seeing that happen, how did you cope? How did your family cope with watching what was happening to your father?"

Mark Shriver: Well, it's tough and as I wrote in the book, you know I mean we had resources and help. So I don't want to give the impression that I wanted to be more involved in my father's care giving/love-giving but you know for any number of reasons didn't do that so we had outside help and I know that we're very lucky in that regards and I know that a lot of families don't have that and some of them do. It's a huge, huge financial strain. It's a huge financial strain you know regardless of whether you have additional resources or not. I think the best advice I can give you is kind of what I heard when we went into it, which is when you've seen one case of Alzheimer's, you've seen one case of Alzheimer's and when you deal one day with a person suffering from Alzheimer's, you've dealt with that one day and it varies sometimes you know, minute to minute, day to day or hour to hour and day to day.

I think you need to rely on other people to give you breaks as a caregiver, to ask for help. I think again as a culture, particularly I think for men, we feel like we got to be able to do this on our own. We're the head of the family or if we're caring for a spouse or a loved one, we can handle it on our own. We have to have a stiff upper lip and I don't believe that. I believe that you have to ask for help. It's not a sign of weakness. It's life and I think most people want to help as best as they can. I've talked to a lot of people since the book came out about resources in the Washington area, support groups where they can drop a loved one off for 4 or 5 hours where they can interact with other people who are suffering from Alzheimer's and they do activities and they give the caregiver, a love-giver, the chance to get a break, maybe go out to lunch with a friend, maybe just to go shopping or whatever it is. I really think you need to be willing to acknowledge that you need help and not see it as a sign of weakness or that you're imposing on people. I definitely have a communal perspective on that, that we need to rely on one another and I think that gives richness to not only the caregiver, love-giver, but also to other people. People want to help out. I really believe that. You know people want to help as best as they can. Some guy called me the other day and asked me, Can I talk to you? This is going to take 20 minutes. And he thought it was a real imposition on me. I'm like are you kidding me, I love... If I can help a little bit, I will in any way I can. So I think that as love-givers/ caregivers, you have to understand that every day is going to be different. That you can't control your loved one anymore or if you ever thought you could. That you've got to be flexible but also ask for help and you know not get flustered and really frustrated. I know

it's hard but to not get frustrated if things don't go exactly go the way you want because they're not going to... they're just not going to...

George Vradenburg: All right. Susan Alexander of San Francisco who I know is on the call but too shy to press star 3 but I'm going to ask her question because it's a challenging one. "How do you feel about encouraging people especially those with Alzheimer's in their families to put provisions in their advance health directives to stop feeding them but giving them liquids if they are diagnosed with late stage Alzheimer's and cannot any longer do anything for themselves?"

Mark Shriver: I'm sorry. The beginning part of that George is am I in favor of that?

George Vradenburg: "How do you feel about encouraging people especially those who have Alzheimer's in their families to put provisions in their Advance Health Directives to stop feeding them and giving them liquids if they're unable to do that themselves?"

Mark Shriver: Well, I mean I think that it is a tough question and I think again it comes down to you know interacting with and having on a personal basis that conversation with a loved one. You know it is tough not just with Alzheimer's but with other victims of strokes and other issues like that. I guess I am kind of skirting the question because I... You know we struggled with it. You know we didn't get into that level of detail with my folks and you know my wife and I talked about it but frankly haven't acted on it which I know is not a good answer but that's... it's tough. So I guess I'm dancing a little bit by that one, George.

George Vradenburg: Yeah, it is a tough question. The question we earlier had from Marian Burns from San Antonio, Texas. "Do you fear that you will get this disease because your dad had it?"

Mark Shriver: I guess you know, there's a part of me, when my dad was diagnosed with it. I decided a couple of weeks later to run for the United States Congress which took up the next almost 2 years of my life and as I wrote in the book, I think some of that had to do with denial. You know, I'm cognizant of it. I don't... You know do I fear it? No, because if I got preoccupied with worrying about it then I suppose it would consume my life so I'm going to work. I'm doing the things I'm doing. I'm talking to my doctor about it. Looking at what medicine, if any, I can take that might lower the chances of it. We're saving for our retirement obviously and trying to build in resources in there in hopes that we're going to be around for I don't know, if I want to live to 95 like my dad did but you know we're building in resources into our planning but I don't fear it because if I succumb to this fear then it has defeated me when I'm 48 years of age and I don't want to do that.

George Vradenburg: We have a question from Bakhus Saba. Bakhus, could you ask your question to Mark?

Question: Yes. Yes. Is this on?

George Vradenburg: Yes, we can hear you

Question: Great. Hey, Mark. I am a 7-year love-giver for my mom and she's been with me for all my 52 years and I placed her in long-term care about a year ago so I live it every day. My question is like I feel like we need to be doing more. What can we do to make a larger impact for Alzheimer's awareness and funding? I think we're really really lacking in that and I do want to thank George and everyone at USAgainstAlzheimer's. You've

taken me under your wing here especially for the song that I wrote there, Still A Child, it has made an impact. But anyway, that's my question, Mark.

Mark Shriver: So I think the answer to that and I talked about this on the book tour is that, you know, the decision of putting your loved one, in your case your mom, back into long-term care as I wrote about it in the book for us, you know for me and my sibs, was brutally tough. Having said that, I think that the thing we got to do is get you know speak out. Not only speak out that you know your mom has Alzheimer's, I don't know about the song that you wrote but try to raise the visibility of the issue...

Question: And I hope you can take a listen at it, Mark. It's an important song.

Mark Shriver: Well, I will.

Mark Shriver: I mean do pass it.

Question: You know, perhaps George has it.

George Vradenburg: We will. We'll pass it on to Mark.

Mark Shriver: Thank you.

Question: I appreciate it.

Mark Shriver: I mean I think the answer though is the amount of money that is going from the Federal government into this issue is a pittance compared to what it should be and I think to be pretty crass about it if folks are really want to change that situation to try to find a cure for the disease. You have to get politically mobilized. You have to get pissed off and you have to demand change and you know just standing up and saying your loved one has Alzheimer's and we want the politicians to do something about it is not going to work. That's part if it but I think what you need, what we need to do is to mobilize politically and you know frankly support those that are putting real dollars into this and increasing the amount of money and those that aren't, you have to defeat.

Question: Hey Mark, can I run something by you? Here's my thought on this. Obviously, we can't depend on the government on this but here's what I have done. I have sent a letter to the Queen, Buckingham Palace and I kind of made in the letter that we need to do something like on a day the world remembers you and have a concert for our loved ones. One person that can head something like that would be a fellow by the name of Paul McCartney. So I asked her to send that package that I sent her to Paul McCartney and to have a day like that would really make an impact on awareness and funding. We've gotten a number of big cities in the states, Canada, England, Australia, they all are behind Alzheimer's. I think something like that would make a huge impact. How do we get that into becoming a reality?

Mark Shriver: Well, I think you know... I think writing a letter is honestly a good first step, but you know the Queen gets probably a couple of thousand letters everyday and... you know you got to... I'm going to go back to what I was saying that I think what you really got to do is mobilize politically, raise money, and change the political system. I think you're saying that you don't think the government, you can rely on the government. I guess I disagree with you. You know the Queen and Paul McCartney can sing a song and it can raise dough and



make a difference and it can mobilize people, there's no question about it, but you know you've got to also put pressure on politicians. Look, most politicians don't lead, they follow because they don't want to get out front of people because if they lead too far, they're afraid they're going to you know be defeated. So most politicians don't have the political guts to move forward on issues like this. The ones that are that want to put real money in then, needed to be supported and those that are saying they do and don't do anything need to be defeated or else you're not going to change the system.

Question: That's why I'm thinking...

George Vradenburg: Excuse me, Bakhus. We have a related question actually from Michael Ellenbogen and I think it follows up on your comment. So Michael, would you please ask Mark your question?

Question: Hi. Thank you very much for doing this. I am a person who has Alzheimer's. I'm 54-years-old and I guess for 2 years now, to be very honest with you, I become so frustrated trying to advocate for this disease. You know I hear some of the comments that you made that you want people to mobilize and one of the things I've realized, most of the caregivers who are out there don't want to spend the time doing that because they're so much involved with their loved ones that they don't have the time to take away from doing that. The people who have Alzheimer's, they're slowly dying. They no longer can speak, they no longer can write. A lot of them are in denial and what's frustrating for me is maybe you can help here is, I've been trying to reach out to somehow be able to organize some of the greatest stars who are in the spotlight and I honestly feel that if we can get all these stars together and maybe one or two can reach out to other stars and say hey look, we need your support to come behind us so we can support Alzheimer's similar to what they did for We Are The World, that song that they created. I think that would make so much more awareness and I hear you what you're saying about the government, but I tell you, I've been knocking on the government's doors for the past 2 years and I've met with so many people. It's hard to get them come on board and we don't have the numbers. That's the big problem, you're right. You know if we were a big political party and you know we're there, we can do so much more, but we're just not there and we have to find another way to do that and I'm hoping you can shed some light on that.

Mark Shriver: Well look, I don't want to give the impression that what I was saying is easy to do, you know. I think the work that you're doing that Bakhus mentioned about trying to get the Queen and/or Paul McCartney engaged, those are all good ideas. You know, it's a new movement, so it doesn't have that political juice of some other efforts, you know, cancer and some other diseases, they get more funding and have more visibility. I think to a certain degree, we got to give ourselves a break here, it's the beginning stages of it, but continue to be relentless. I think it would be a huge, you know, obviously a huge help. I mean, I look at the example my brother did with Bono the lead singer of U2 to bring up the issue of debt reduction, HIV, Aids and some of the issues in Africa and they did a great job and Bono got mobilized on it and he literally is a huge rock star and that's what the Paul McCartney idea is, I think it's a great idea. I don't think it's an either or as far as what I was proposing. So I guess, I see that you sent me a note here, Michael and I think you just got to keep knocking at the doors.

You know I'm trying to do a lot of this stuff right now on the issue of child poverty in America for my work at Save The Children and either doors are not opening or are getting closed, but you got to just keep plugging

away and I think you know efforts like George and Trish are doing here are really valuable. I think I don't know about the political dough because I haven't spoken and gotten in that level of detail, but I think that will make a difference in a bunch of politician's mind as well as crass as that seems, it does make a difference. Unless you have a huge constituency behind you which is votes or a lot of dough behind you, it's tough to make an impact or huge rock star like a McCartney or a Bono. I mean, what we really need is some of these guys that are writing you know a million, 2 million dollar checks to these political operations now to do that for Alzheimer's would be a huge deal. A huge deal, would move us in the right direction because then you'd... unfortunately that's what makes a big difference now in Washington. So I don't want to be discouraging although I guess I'm sounding discouraging, but I think we just got to keep plugging away. Got to keep fighting. You know if you're suffering from Alzheimer's and you're working on this issue you're a powerful spokesperson.

George Vradenburg: And Michael's case is one which emphasizes the urgency of this cause and the importance of it and Michael has been a terrific advocate. So let me move on to some other questions we have here. Pamela Rivers is on the call from Maryland. Pamela, would you ask your question please?

Question: Sure. Hi. Good afternoon, Mark and thank you for doing this call. I mean, I'm listening to you and my mind is just going ping, ping, ping and I'm taking all these kind of notes because I totally understand where you are coming from. I was a caregiver or as you say love-giver to my mother who had Alzheimer's and unfortunately she just passed on April 1<sup>st</sup> and I was her sole caregiver and so that was just challenging enough of trying to find new resources and funding to help me out because I found that unfortunately, it seems like those people who worked in their life are caught in the middle and they make too much money, not that it's a lot of money, you know, for government funding but then you can't afford other services. And I know a lot of friends were encouraging me to write about it or start a blog which I did and at first, I didn't want to because I felt like I don't want to talk about this most painful journey that I'm going through but then I felt like you did that if I tell my story then maybe I'll help the next person.

So one of the things that I wanted to ask you is that after losing your father, how did you handle that did you feel anything like loss, confusion? Did you feel guilt, that you should've done more because I know that now, 3 months into this past and a lot of my friends are like you know, you did everything that you could do and even though she didn't pass from complications with Alzheimer's, I don't feel guilty but I just feel like you know, that I have everything in line and now I feel like the lost caregiver... you know, I had the title. Now, I'm like I'm lost and then one other thing I want to tell him was on advocacy, I feel like okay, now that I can do more, I want to become a stronger advocate and besides participating in events that The Alzheimer's Association are doing or me starting fund raisers. How could I go about maybe helping to speak about this to people or groups?

Mark Shriver: Well, I think an answer to the first part of your question did I feel, you know, confusion and inadequacy and loss? Yeah, yes. All of the above and I think you'll see that in the book and you'll see when we sold their house and after my mom died, you know, when my father moved in to assisted care facility a mile from my house. That was a tough decision and, my sibs and I went back and forth on that. Should he move in with one of us and there were complicated issues and you know you are confused and that's one of the reasons I sat down to write. It was to try to put some structure to those different feelings and different

emotions. So I think what you are feeling is totally normal and is totally fine. At least it was for me and I'm sure it is, I'm very confident of that answer.

I think as far as if you want to do more, if you have some more time now. I mean I don't know where you live in Maryland but it could be as simple as going to your state senator whoever that is or a member of the House of Delegates which is where I served and those people will listen to you if you have you know, 5 or 6 people showing up because they want to get elected and they're not getting elected with tens and thousands of votes. They are getting elected with fewer numbers. Tell them you want them to put together an Alzheimer's caucus in Annapolis and you want them to be involved in it and you want them to put pressure on Governor O'Malley to do something about Alzheimer's here in Maryland and he is running for president and you know, you want to have your state senator to go with... you know, put together that caucus and go have a meeting with O'Malley and educate him on it so when he goes in and runs for president, which is what he is supposedly going to do, he talks about Alzheimer's. And if you live in New York, go do that with, you know, figure out who the most powerful state senator or who one of the most powerful state senators are in Albany and go deal with Governor Cuomo. Put together... I mean maybe there's already an Alzheimer's conference in Maryland and maybe it's not doing it but you could go energize that group to get O'Malley educated on it or any other governor or senator and they'll start putting pressure on people in Washington. It's those types of little gestures that I think can create a ripple to work that Bakhus is doing and the other gentleman who has Alzheimer's. You know these things start creating a ripple and the ripple starts creating a bigger wave and I think that's when we start making big changes but it's got to start.

George Vradenburg: It's absolutely right. I think it is a 1 plus 1 plus 1 plus 1 plus 1 getting to the millions that will do it and the first people who start speaking will feel alone and isolated and unable to affect change but continuing to do it, don't give up. Don't quit and persist. Connect to other people who are doing it. Work with USAgainstAlzheimer's. Go to our [site](#) but we will get the movement that Mark described going but it will be one person at a time initially and then people will start connecting and finding easy to use ways to get involved and then we'll begin to create a real momentum behind this effort.

Let me ask Edith Royal. Mrs. Royal, if you are on the phone to hit star 3 and we're going to allow you to ask your question but in the meantime, I want to go to David Goldblum who has a question who has recently lost his father to Alzheimer's. David?

Question: Hi. Thank you very much. I just want to make another comment on the last couple of comments. It can really be summed up, the largest journey starts with one small step is right and so you know, you just take one thing and keep hitting on and it's chipping away one piece at a time and ultimately, you'll get something significant but I'm going to... I'd like to bring up a slightly different angle here because we went back and forth with my dad. My dad passed away about 13... about 15 months ago now, 3-1/2 weeks before he would have been 91 years old. He was diagnosed when he was 85 and he was a Rabbi and he worked until he was 81 years old and the thing that's most troubling to all of us, no one in his family ever had Alzheimer's. Her mother was like 102 when she passed and she was alert to the last minute and his sister was 90-1/2, alert to the last minute and his brother was 96-1/2, alert to the last minute. His older brother who died 3 years ago actually drove a car until 1 month before he passed away in Western Mass but the question I have now is I just wonder... First of all, Mark, I want to thank you very much for sharing that book with us and going public

because that's a great thing but I'd like to know for your father, what drug was most effective in his treatment over the course of this horrible illness, because one of the problems my father had was he had the side effects but Aricept was probably the drug that helped him the best.

Mark Shriver: The short answer is that what we, you know, found helpful as well.

Question: Was there effect?

Mark Shriver: Yes.

Question: Now, we just couldn't believe. You know my father one of them... and the other thing that's really troubling to us. You know my father is always reading. He was... his brain was always active and physically as well, he was a powerhouse you know because he had grown up in the Minneapolis Field Market so he was physically in peak condition most of his life as well and we just cannot believe that this happened to my dad.

Mark Shriver: Well, you know, I understand that. Look, my dad lived until 95. You know, he was 6'1", stronger than ox right up until the last month of his life and had a bigger brain as anybody I've ever met and as I wrote in the book he would send little notes and slip them under my door when I was high school and mail them to me when I was in college and I got them almost every day of my life. It was an article from American Magazine or Time Magazine or some thought he discussed at dinner. He wrote a buddy of mine, which I wrote about in the book A Good Man. A buddy of mine who went to Brown University, a Jewish guy, and they corresponded, which I never knew, about the Judaic Studies Programs at Brown University. You know, my father knew more about Judaism and about the Judaic Studies Program at Brown than this guy did who went to Brown. So, he has an active mind as anybody as I've ever met or anybody I've heard of and it hit him. So you know, I don't know. I mean, that's why we got to put more pressure on the politicians to put more dough and try to figure out a solution to this.

Question: You see the thing with your dad, your dad's mind was... Yes.

George Vradenburg: I'm sorry but I think we have to move on. We have some other comments and questioners.

Question: Okay. Look, I thank you very much for taking the time on this question.

Mark Shriver: Thank you very much. I appreciate it.

George Vradenburg: All right. Edith Royal has a comment. Edith's husband, Darrell Royal was the iconic University of Texas football coach for so many years and really epitomized sort of the power of coaching to change young men's lives and unfortunately Darrell now has Alzheimer's, but Edith, you have a comment or question?

Question: Well, I have a comment. I just want to thank Mark so much for his book and for his information that he has imparted to all of us today. We had started Darrell off several years ago on Aricept and Namenda was added when it came out. None of it seemed to be helping so the advice of the doctors at that time was just do no harm and stop all of those but now my understanding from other neurologist is that it delays the onset and Darrell is now 88 and he has two teammates from his playing days at Oklahoma that already have advanced

Alzheimer's. So I think there's a lot of information that we could gather from the concussions that people are having now and do you have a comment about that?

Mark Shriver: Well, as far as the medicine, you know, I think that I mentioned with the previous caller Aricept, was what dad was put on in 2000 and it is my understanding, I haven't looked at it recently you know in the last year or so but that it is the way you described it is exactly what it's supposed to be, that it's suppose to slow it down, not cure. Obviously, Aricept did slow down the progression of it. And I don't know enough about the concussions or the issue of concussions and how that impacts either Alzheimer's or other degenerative diseases.

George Vradenburg: The answer... the current understanding is that a chronic traumatic encephalopathy, which is the condition that is created by concussions, creates a process in the brain that is very similar to what happens with Alzheimer's and shows the same symptoms. But in addition to that, football players or soccer players or even people with accidents in life and the PTSD victims seem to actually convert in significantly greater numbers to actual Alzheimer's disease as well as those who suffer from a slightly different neurological pathology. So there is a relationship here and there are now dual use research programs that are looking into the wounded warrior population from Vietnam and now increasingly from Iraq to try and understand the relationship between the pathologies and why it would be that in fact those people for example in the Vietnam area would now be converting to actual Alzheimer's disease at much greater numbers than the non-warrior population.

We have just a few minutes left. So I'm going to ask Patti Hopp, do you have a short question that we might ask Mark before we move to our final comment?

Question: Do I need to hit star 3?

George Vradenburg: No. No, we've got you here on, Patti.

Question: All right. Thanks. I'm from Florida and I hear a lot of people talking about the fact that it's their mothers and fathers. It's my 76-year-old husband and he was diagnosed in '08. I was a caregiver until a year ago. I now have him in a memory unit. I'm very proud of the service I get and at least I can get a little relief. I walk with Alzheimer's in Patagonia with 2 daughters and 2 son-in-laws and I'm very proud of that. We stay very active and one of daughters is very active with Alzheimer's. Since I've got 2 daughters, I had a father who passed on at 89 with Alzheimer's. I have another in-law on my husband's side there that passed away with what at that time they called Gray Matter's Disease and I'd somebody to tell me if they have any ideas on what to do for the kids? What's coming down the pipe? My kids are 33 and 42 adult children and their children and I'm a little concerned about what they ought to be doing as prevention? I'm done.

George Vradenburg: Mark?

Mark Shriver: George. I don't know if you want to jump in on that. That was a great statement obviously.

George Vradenburg: The answer is that the risk factors for cardiovascular disease, for diabetes and for Alzheimer's are very closely related which suggest that if in fact you exercise thoroughly during the course of your life, you keep your mind active and you use a balanced Mediterranean-like diet. That your body is better

positioned to resist the disease. Now, having said that it does not stop the disease. It does not prevent the disease but a strong body and a strong mind will have the tendency to be moderately protective but as you just indicated, as Mark has talked about his own dad, the most brilliant mind, the most fit person is still susceptible for this disease. It's just that it might have been that Sargeant Shriver got it 5 to 10 years later than he might otherwise have gotten it because he was so fit and because he was so agile mentally but... So these are things you should do anyway and they will be helpful but they will not be means of preventing the disease.

Now, out of self-preservation, the last question or comment is going to go to Trish Vradenburg, and Trish, what is your comment?

Question: God. Am I on?

George Vradenburg: You're on.

Question: Okay. I just wanted to... Hi, Mark. I have so loved your book as you might have gathered from my review.

Mark Shriver: Yes, thank you.

Question: Except that you got to cut yourself you know, a little slack because you did an incredible job I mean with your dad, always and you really learned from him. So that's just an aside.

Mark Shriver: Thank you.

Question: I just wanted to say to the woman whose mother had died recently and she wanted to know, you know, because she was a caregiver and that's how she described herself and I would suggest that she describe herself in the noblest way you can go as an Alzheimer's activist who is just trying to defeat this powerful ugly disease. So thank you all.

George Vradenburg: With that, I think that's a perfect sort of 1-minute to the end comment.

First, I want to thank Mark for being on, for writing the book that he did, for being so candid with us through the book and even on this call.

I just wanted to do a 1-minute quick policy update. As you all know, the Administration has adopted a national goal of stopping this disease by 2025 and it has an Advisory Committee to Secretary Sebelius to design the implementation of the national plan to do that. So that Advisory Council met most recently on Monday and will be working on implementation of that national plan. So that's from the Administration's point of view is a positive movement forward. No promises but positive movement.

On the appropriation side, both the House and the Senate at the committee level have addressed the NIH funding for next year. The senate, the sub-committee on appropriations has appropriated an additional \$100 million for NIH. It did not designate it or earmark it for Alzheimer's but in the report language urged the NIH to increase its focus and it's priority on Alzheimer's. The house sub-committee that deals with this subject

adopted a budget for next year that is flat for NIH and would actually very slightly reduce the allocation to the National Institute of Aging. So we do have a lot of work to do for Congress.

And finally, we recently heard just this week that Pfizer released the top line results of its most recent phase III trial drug Bapineuzumab and that at least in populations with the genetic risk, ApoE4 allele which gives you a slightly higher risk for Alzheimer's, their drug was not effective in changing clinical outcomes. They will be announcing within the next week or two the results of their trial in other populations who do not have this ApoE4 allele and there is at least some hope in the scientific community that it will produce some disease modifying effect and thus demonstrate that in fact, we are on the right path even though it may be that these modifying effects may not be significant in patients who are given the drug at the mild to moderate stage and that the drug should be administered when you are either before symptoms appear or when you have mild cognitive impairment. So there is potential... these things, you know, go up and down over the years but there is some potential that we ought to be looking for in the next week to a month from Pfizer and Lilly will announce the results of their Phase III trial for their drug Solanezumab in early October and/or potentially in a press release earlier in September.

So we have a lot of work to do on implementing a National plan to get a solution by 2025. We have a lot of work to do with Congress, which is not yet paying attention to this disease and on the scientific front, we can only continue to root for the drug companies that are investing in this disease.

Thank you for participating in Alzheimer's Talks. We're grateful for the support of the Zickler Family Foundation that made this call possible. And we certainly are very grateful for Mark Shriver's participation in this call. In a few days, we'll have a recording, a copy of the recording on a transcript on your website for you to share with your friends. Please stay on the line to leave a message with what you would tell Congress about why they should increase funding for Alzheimer's research and we will make sure that that message gets to your congress person and your senator. Again, thank you all for participating and particularly to Mark Shriver. Thank you for your advocacy. Thank you for your book. Thank you for the story of your father, A Good Man, and thank you for participating in today's call.

Mark Shriver: Thank you very much.

George Vradenburg: With that, have a good day all. Thank you."