

**Alzheimer's Talks Edited Transcript**  
**Join the Fight Against Alzheimer's**  
**with Dr. Michael Weiner**

**September 26, 2014**

*The following transcript has been edited for content and clarity.*

**George Vradenburg:** Welcome to [Alzheimer's Talks](#). Thank you all for joining us this afternoon, at least this afternoon Eastern Time, for this very, very interesting discussion with [Dr. Michael Weiner](#) of the University of California, San Francisco. He is our guest today to discuss his exciting new [Brain Health Registry](#), where you'll have a chance to help researchers and the fight against Alzheimer's from your own home. This is really a way for all of us as 'citizen scientists' to get into the fight against Alzheimer's for ourselves, our family, our friends, our loved ones and to leave a legacy for those in our generation, the generation in front of us and behind us.

My name is [George Vradenburg](#). I am the Chairman and Co-Founder of [USAAgainstAlzheimer's](#). I founded this organization with my wife and some friends, a friends and family start-up about 3 and 1/2 years ago as a result of losing my mother-in-law to this disease. USAAgainstAlzheimer's is a disruptive, relentless, you-can't-stop-us kind of force committed to ending this disease by 2020.

Alzheimer's disease, as I'm sure virtually everyone on this call knows, is a grave and growing menace to each and every one of us, to our families and to our children. There are an estimated five million people in the United States and 44 Million plus worldwide living, or should I say dying, with dementia, more than HIV/AIDS, cancer, or chronic heart disease. And there are more than 100 Million secondhand victims that we call caregivers or the carers. In the coming decades the number of those dying from Alzheimer's and those caring from them are expected to triple. We have committed to stopping this disease by 2020 and we're hopeful that we'll have a strong first generation medicine on the market before that period of time, which will slow the progression of the disease or defer its symptoms. We catalyze change by collaborating with everyone, anyone who is ready, willing and able to join with us in removing barriers impeding the path to therapies, treatments and ultimately cures.

We have over 400 people registered today and on the line from 43 states plus the District of Columbia, Canada and from Europe. Others will dial in directly. There are also over 1,200 people who couldn't make the call today but asked us to send summary information and a link to the recording. We'll also send that information to everyone who registered for today's call. There is obviously a good deal of interest in Michael Weiner's exciting work.

Thank you for joining us today to learn about Michael Weiner's exciting work in creating this new [Brain Health Registry](#). This activity is supported by a contribution from Eli Lilly, a leader in this field who has a

candidate treatment in late stage clinical trials right now and hopes to report out the results, hopefully successfully, in 2016. We are grateful for their support so that we can bring this call to you today.

It's my pleasure to introduce you to Dr. Michael Weiner, one of the leading researchers in the world on Alzheimer's disease. He's the Professor in Residence in Radiology and Biomedical Imaging, Medicine, Psychiatry and Neurology at the University of California, San Francisco. Obviously you're over educated, Michael. He is also the Principal Investigator of the [Alzheimer's Disease Neuroimaging Initiative](#), nicknamed ADNI, which is a long-term study that observes people and takes a variety of clinical measures of people overtime to ascertain the signals, biological imaging, clinical that may lead to Alzheimer's or lead people away from Alzheimer's. It is one of the most important studies in the Alzheimer's field and it has taught us that in fact this disease starts in the human brain decades before you actually see symptoms and has given us both the challenge, which is how do we identify people who are at risk for the disease, and the opportunity if we can identify those at risk for the disease we may be able to introduce a prevention so that people can take the treatment before they get symptoms and defer or avoid symptoms entirely. He's also the Founder and Principal Investigator of the [Brain Health Registry](#), which is what we'll discuss today.

This is a reminder for those of you who've been on the call before and a signal to those of you who have not been on the call. If you have a question during the call, please press star 3 on your phone. By pressing star 3 you'll be placed into the question queue. Please have your question ready to share briefly with a member of our staff and they will try to get you live on the air with Dr. Weiner as soon as possible when we open it up for questions. For the first time today, we also have an online streaming option, if you are listening to us online and you can get there through [USAAgainstAlzheimers.org](#), you can type your question in the box and we will get to as many questions as possible after this opening discussion with Dr. Weiner.

Dr. Weiner suggested that we do this a little differently than we have in the past and that I simply ask him a series of questions, hopefully the ones that would be top of mind to all of us in understanding this new Brain Health Registry. And he'll answer those questions and then we'll open up to your questions in a few minutes.

Dr. Weiner, thank you for joining us. You are the Principal Investigator on the Alzheimer's Disease Neuroimaging Initiative, known as ADNI. That's a huge and vital project central to our understanding of this disease, that's a lot for one person. And here you are with another big project. So tell us about the Brain Health Registry, what is it and why you started it?

**Dr. Michael Weiner:** I've been doing research on Alzheimer's Disease for 25 years, but my view of all this has really changed as my mother developed mild cognitive impairment about 10 years ago and then about six or seven years ago she became so impaired that I had to put her into an Alzheimer's care unit against her will. It was probably the worst day of my life. All of a sudden at a very deep level I started to really appreciate the impact that all this has on people, on families, at the emotional level and the cost. I started asking the question, how could I have bigger impact? What is the problem? What is the rate

limiting step? Why can't we just get to effective treatments sooner? And so that's what really led to the development of this project.

**George Vradenburg:** Tell us about the Registry and tell us why you think the Registry is going to be helpful in that?

**Dr. Michael Weiner:** I think the Registry is a solution to a problem. The problem is the high cost of doing human studies. There are many basic science laboratories making all kinds of molecules that work on mice and rats and may be effective ultimately in humans. But only a few treatments can be tested in humans because the cost of human studies can run into the hundreds of millions of dollars. And so the high cost of human research, clinical trials, is the fundamental limitation to our getting treatments developed more quickly. And since I run this very big study called ADNI, I came to understand that one of the big inefficiencies of the whole process is just simply recruiting subjects and identifying who is suitable for a study. We called that a recruitment, assessment, and screening. So recruitment, assessment, and screening is a big cost, there is a lot of waste, a lot of people are screened and every time a clinical study is done, they start all over again with new recruitment. So if Eli Lilly does a trial, they're recruiting for subjects. But if Merck does a trial, they're recruiting independently for subjects and if Pfizer does a trial or a university, everybody is out there in the marketplace recruiting individually for their trials. So it seemed to me that one simple solution might be, why can't we try to develop what we call a Registry using the internet - where people sign up, join, and take some tests and answer some questions and we have them in the database. We protect their information. And then if somebody is in need of subjects, for example in Philadelphia, we can look in the database and see, 'Hey, we have 300 subjects in Philadelphia who meet the criteria.' And then we can feed those subjects to the investigator.

**George Vradenburg:** I actually signed up on your Brain Health Registry and went through your questions and I found it quite easy to use. And I think quite informative for someone else and I really would encourage everyone on the phone to do the same, by going to [BrainHealthRegistry.org](http://BrainHealthRegistry.org) and sign up. Actually Michael could you just take us through what happens when someone comes to [BrainHealthRegistry.org](http://BrainHealthRegistry.org) and joins the registry?

**Dr. Michael Weiner:** Sure, initially when you come to the website you'll get some information right on the home page about what we do, what we're about, why we protect your privacy and so forth. If you click "Join Us" you'll come to a registration page where you give your e-mail. We actually ask for very little information about you personally. We don't ask for social security number, we don't ask for your Visa card, but we do need your e-mail so we can communicate with you. And then you're immediately asked to sign an informed consent, which is approved by the University of California, San Francisco Institutional Review Board, and that takes a few seconds or a minute to read the informed consent form.

And then you would be led to a series of questions: How old are you? What is your gender? Do you have a family history of Alzheimer's diseases? Do you have a pro

blem with your memory? Do you feel depressed? What other illnesses do you have? Etc. The kind of questions you'd normally be asked if you were actually going to your doctor or if you were going into

some kind of a clinical study. These are the basic questions that everybody who's doing research would need to know. And those initial questions might take you five or 10 minutes to get through, depending on how fast you are with your mouse and able to click in the little boxes and give the answers.

Then, you come to some brain games or neuropsychological tests, which involve playing cards or other symbols, and these are tests of your memory, of your reaction speed, of your ability to make decisions. They give us some information about how well your brain is working from a cognitive level. We call this quantitative neuropsychological testing. This is something that is routinely used in clinical trials in order to screen people to see whether they are functioning normally or whether they have some mild impairment or whether they are so impaired that they might be considered to have early dementia. So the entire initial process, it takes me maybe 15 minutes to get through it, other people it might take a little longer, 20/25 minutes. You don't have to do it all at one session, you can break it up do it whenever you want.

Once you've completed that basic module, there are other modules that we would like you to come back to if you can. For example, we'd like some information about your diet, exercise, information about alcohol use and other substances that you might be taking, questions about mood, depression, anxiety, questions about sleep. I think you get the idea. We're trying to get an overall picture of your brain function and specifically we are asking exactly the kind of questions that the clinical trials ask when they are screening people, trying to decide whether people are qualified to go into the study.

We've had 10,000 people sign up for this already and we've only been in business a little over six months. So we already see the database is fascinating, the data is very valuable. I can tell you more about that, and this informs us as to who would be suitable for a clinical trial. We had people 20 years old who are signing up. Anybody over age 18 can sign up and you don't have to have Alzheimer's disease, you don't have to have any relationship to Alzheimer's disease. We are interested in young people and old people, people with MS, people with sleep disorders, depression, everybody. It's all about brain health and the Registry will ultimately be available, protecting health information, to scientists interested in all kinds of brain diseases not just Alzheimer's disease.

**George Vradenburg:** So you've raised a number of interesting issues and I'll go through a few of them. I want to ask you the question about privacy and security. So who has access to my personal information and what would you or might you share with a pharmaceutical company that was interested in a clinical trial?

**Dr. Michael Weiner:** The only people who have access to your e-mail and other personal information are people who are within the study at the University of California, San Francisco. The whole website is using the UCSF servers and UCSF approved software and UCSF approved backups. So it's the same level of security that a patient care record at the University of California, San Francisco would be, which is pretty darn good, but as we all know there is nothing perfect in the world of internet security and that is one risk. But I just want to emphasize that we're not getting social security numbers and we're not asking for any kind of financial information or bankcard numbers or bank account numbers. I'm signed

up and my family has signed up, I think the risks are very low. But they are the risks that occur whenever any personal information goes into a computer database.

**George Vradenburg:** You mentioned that you get my e-mail address, as I know since I've signed up, so that you can communicate with me. What kind of communications might I expect if I sign up for the registry?

**Dr. Michael Weiner:** We send you a newsletter, giving you some updates. I think you've gotten the newsletter, George, in the last three or four weeks and you're about to get your six-month follow-up. So an important part of all of this is longitudinal information. I can talk more about the value of that later. But that's basically it. We're trying to avoid spamming people with tons of e-mails. We're just going to give a newsletter every month or every other month and then the follow-up. It's possible as the website grows, that we may ask some people if they want to engage in more frequent contact.

I didn't fully answer a question you asked just before and that was would we give the emails out, let's say to a pharmaceutical company or any other investigator, and the answer is no. We do not plan to do it that way. The way we plan to do it is as follows: let's imagine that, well this is sponsored by Lilly, so let's imagine that Lilly is doing a clinical trial in Durham, North Carolina and they are interested in getting additional patients in Durham, North Carolina and they contact us. And the first thing we do is look in our database and see how many people in the zip codes around Durham meet the qualifications for their trial and if they wanted those subjects to be referred to the site, what we would do is we would work with Lilly and we would work with the local site to construct a letter that we would then send to those subjects. So we would send an email to the subjects. It would be us who communicates to the subjects. And it would say something like 'Dr. Doraiswamy at Duke University is doing a study on Alzheimer's disease with Eli Lilly and you may be an individual who is qualified for this study. If you are interested in being involved with the study click here.' So the subject will have control as to whether or not they want to take the next step. We would never give their email out to anybody else. We will be the people who'll communicate with the subjects, provide them with information and then the subject can decide if they want to follow-up and go to the next step and go to the site. And then at some point the subject gets handed off essentially by themselves to the site and they would follow-up and then we would track that information back from the site. I hope that was clear.

**George Vradenburg:** I thought that was very clear.

You mentioned that there were some neuropsychological tests or brain games in that you take when you get on this site and that there was some longitudinal component. Let's talk about each of those. How do these neuropsychological test work? What are you learning? And why are they so important?

**Dr. Michael Weiner:** Well, Alzheimer's Disease, is a disorder that affects our thinking, especially our memory, but other aspects of thinking. Cognition is the word that we used as a fancy word for thinking and the only way we have of trying to get some quantitative measurement of how well people think and whether they have a problem with their memory or other cognitive functions is by what we call neuropsychological tests. These have been around a long time and nothing is perfect but they are what

we have. So for example, I could test your memory right now George, I can say ball, cat, flag, sky, moon, dog, pizza and now I ask you to repeat back those words, I'm not going to ask you to do it ....

**George Vradenburg:** Thank you.

**Dr. Michael Weiner:** This is the traditional way that we test memory. And you can do this online by showing people pictures and then presenting them with other pictures and say 'is the second picture that we're showing you the same as the picture we just showed you before?' That's one example. So over the recent years there have been a number of what we called computerized neuropsychological test that have been developed. And a lot of work has been done on these and shown that they seem to work quite well. Just as well as the so-called paper and pencil test, which have been the traditional tests. And just in the last year or two some of these computerized tests have become available online through the internet. So you can access them through a browser and that is, to me, is transformative because it allows you to obtain neuropsychological test data on very large numbers of subjects, because obviously websites can be scaled. So we only launched our website this year and yet we have neuropsychological test data now on 4,000 subjects. And to imagine how long it would take if you were bringing people into your clinic to get neuropsychological test data on 4,000 subjects, it would take years and years and millions of dollars of NIH money. But we got 4,000 neuropsychological test data sets in a few months. And of course there was a cost in getting the whole website started up. But once it's going the cost is trivial and that is the beauty of a website. Once you've established it, you can scale it, it takes very few people to run it. So the costs are low and you can get huge amounts of data. Now why is that important? When Alzheimer's studies are done, sometimes they're done on people who have mild dementia, that is they have quite severe impairment of memory function. Sometimes they have mild cognitive impairment, meaning they're still functioning well on life but they have a memory problem or sometimes we are now starting what we called prevention trials, which are people who are completely cognitively normal. So it's very useful to have screening information on whether an individual subject is a normal subject or has mild cognitive impairment or might have dementia. And I'm not saying that the data we get on the internet is perfect but it provides a rough screening information that I'm certain will turn out to be very useful when we start referring people to the clinic.

So the real test of all of this is getting people from the internet into clinics and evaluating them and determining the validity of the information that's obtained when they're at home. But the results that we're getting look so good, that is the results that we're getting seem to match the kind of data that has been obtained from people who were studied in clinics. I personally am very optimistic that this is going to have a lot of value and will save money and speed up trials. Because we can help trials enroll their subjects.

**George Vradenburg:** And you mentioned that you do repeat. You mentioned that I was about to get, if I haven't gotten already, a six-month reminder. Why is the longitudinal component important and how does that work?

**Dr. Michael Weiner:** Well it's important for many reasons. But fundamentally the problem with Alzheimer's disease, as everybody on this call knows, is that Alzheimer's disease ultimately produces

progressive decline of thinking, of cognition, and especially of memory. One observes memory decline but it takes place over a period of years. Let's say we have a drug that really would work and prevent Alzheimer's disease, we wouldn't want to put in the drinking water, we wouldn't want to give it to everybody it would be too expensive and these drugs can have side effects. So we only want to prevent Alzheimer's disease in people who are at high risk to develop symptoms of Alzheimer's disease, certainly no reason to treat somebody with the drug if they're not going to develop symptoms. So how do we know who's going to start developing symptoms? Well we know that the older you are the more likely you are, so age is a factor, family history is a factor, the ApoE4 gene is certainly a factor that increases one's risk. But beyond those things I've just mentioned, it's really hard to know who's going to go on and develop a problem. But, if we could monitor people overtime longitudinally we may be able to see decreases in function of memory measured on these neuropsychological tests before people become symptomatic. And this is the kind of thing that is done in medicine all along, for example the older men who are on the call may be getting their Prostate-Specific Antigen measurements, for example, once a year. And we all get our blood tests, let's say once a year or once every other year. The doctor starts looking for trends and if you see a test that's a little abnormal well you come back and repeat it and then start repeating it more often to see whether or not a test is changing. That's in medicine, how we detect things before symptoms develop. We notice trends in test measurements and I believe that longitudinal monitoring of cognition, especially online because people can do it at home, is going to be a huge way in the future that we detect people who may be having subtle decline and it's the decliners who you would want to bring in for clinical trials.

**George Vradenburg:** I know you're brand new, so do you have any experience yet on the extent to which people will come back?

**Michael Weiner:** No. Actually I think it's Tuesday for those of you who signed up six months ago, are about to get a letter that it's time for your six-month checkup. So we are going to see how that works and that's why we need a lot of people. I don't expect by any means a 100% return. I'm not even sure we'll get 50% return, we may get 30% return in the beginning. Not everybody is really going to make that commitment to keep coming back. We have to find all those people who are and we need to find the right ways to do the messaging. We're just at the beginning of this and I didn't know anything about websites and how to do a website, in fact I'm not sure I know much more now. We need to experiment and find out what's the best way to message? What's the best way to engage people? How we use social media? How we use e-mails etc. etc. It's a very, very complicated, interesting kind of social experimentation to do and that is the other reason why I believe we need very large numbers. I'd like, for example, just in the San Francisco Bay Area I'd like to see 50,000 people over the age of 60 enrolled on the website. And then we try to follow them longitudinally and maybe in the end, I mean if we can find 3,000 or 4,000 seniors in the San Francisco Bay Area who are motivated and who we follow longitudinally that's a huge, huge resource to feed for clinical trials in San Francisco. And if we could do it in the Bay Area then we could do it in L.A, in New York, and we can scale it up and do it across the country and then Europe. It's very much a trial and error process and we're very excited about it and we're very excited about the data we're getting. So I think it's very promising.

**George Vradenburg:** You mentioned at one point that you have taken people in their 20's and 30's, anyone over 18, yet the risk for Alzheimer's really accelerates after age 60. So who is your target audience?

**Dr. Michael Weiner:** Well, when I started this I wanted to build a cohort of older subjects over 60 in the San Francisco area for prevention trials. That was my motive. Then as I've started talking about this, my friends in psychiatry, in neurology and people who were studying traumatic brain injury, people who were studying depression and PTSD, and schizophrenia, and multiple sclerosis, they all said, 'Hey, you know Mike you're building this website, I could see how I could use that to study my condition.' And so then as I thought about it more, let's not call this Alzheimer's, let's just call it brain health. That might attract more people, it just might be more attractive, more fun to come into something that's aimed to brain health, and let's not limit it to older people. My very limited advertising dollars that I have right now is going to focus on enrolling older people, but sometimes the best way to enroll older people is to attract the children and grandchildren into it and get them to encourage their parents and grandparents to join the Brain Health Registry. It's another approach we're taking with Facebook and social media and so forth.

For example I'm working with Geoffrey Manley at San Francisco General who is a national expert on traumatic brain injury and concussion and he's very excited about using the Brain Health Registry to enroll younger people who've had a head injury from sports or auto accidents or muggings. And as we know traumatic brain injury is ultimately a risk factor for the development of Alzheimer's disease and other problems. We're talking to people interested in frontotemporal dementia, people interested in MS, and using this Registry to help enroll subjects because there could be a big proliferation of this type of thing, you could have PTSD websites, depression registry and this and that. But everybody needs normative data. You want to have normal subjects of all ages as well as subjects with a disorder and we operate at extremely low cost. We're very, very happy to help all kinds of neuroscience investigators work and so for that reason we decided to open it up and the data we're getting on younger people is fascinating. We're finding extremely interesting results connecting sleep, depression, and cognition, for example, in people who are young. And we're interested in looking at the effects of age, looking at the effects of menopause, effects of surgery. There is a lot of potential for the use of this, but I don't want anybody to think that I've lost my focus. I'm an Alzheimer's researcher, I'm doing this to try to recruit subjects for Alzheimer's disease and if people who are interested in these other disorders want to take advantage of our Registry, we're happy to work with them and that'll provide us an additional income stream.

**George Vradenburg:** You mentioned both the fact that you're in the Bay Area, you've got some focus there, but also you used as an example a Durham, North Carolina study out of Duke as a possible application of your Registry. So is the Registry available to anyone in the United States?

**Dr. Michael Weiner:** The Registry is available to anyone in the world. If you were in Hong Kong or in Iran and you went to the website, if you weren't blocked, and if you search for 'Brain Health Registry' you'll come up with our website. So it's like any other website, it's available around the world. Right now you have to speak English and all of our public relations and advertising has really been focused mostly in the

Bay Area. What's interesting though, is that although we basically work with the PR Firm last spring to build our Registry in the Bay Area, I think more than a third of our registrants are from outside the Bay Area. Because various media picked it up and people have picked it up in searches and so forth. So we have some national penetration and we have maps that show what zip codes people are in who have joined the Registry. There are people from every state in the United States now and quite a number of people in Southern California but the main cluster really is in San Francisco and the counties around San Francisco.

**George Vradenburg:** Well I live in Washington D.C., I signed up and probably the way you present yourself to me in Washington is no different than the way you present yourself to somebody in Berkeley. So it's obviously available to us, and quite frankly if there were a clinical trial in which I would be interested in participating it would be a clinical trial with a site here in Washington. So I think your service has potential to the field, to those that want to stop this disease, is clearly national and I think potentially international. Because it does seem to me, this is just off the top of my head, that the more people that come in and give you data in a common format with a common set of questions, the more comparative data you'll have - and to be able to do that nationally and internationally is an enormous benefit to the field rather than having multiple different registries or different formats and different data structures. So that's just an observation.

Let me ask, there are other registries out there, there is the [Alzheimer's Prevention Registry out of Banner](#), in Arizona. The [Alzheimer's Association has Trial Match](#) where I can go online and see if there's a clinical trial that works for me in my area. How do you work with them or not work with them? Can I sign up for all three?

**Dr. Michael Weiner:** Yeah, absolutely. In fact you should. You should sign up for all three. These are phenomenal organizations, we work very closely together, they've been very helpful. I mean I love the Alzheimer's Association, I think it's a phenomenal organization, I encourage people to donate to it, as I do encourage people to [donate to USAAgainstAlzheimer's](#). What they started in Banner was to some extent an inspiration for me, although I was thinking about it at the same time. So the Banner Alzheimer's Prevention Initiative, which is a fabulous organization, they're doing some great prevention trials as well as their website. They basically request you sign up and you give them your e-mail, I've signed up and I'm on the advisory board. They don't collect a huge amount of information on the subject, and they're not doing at the moment a lot of online testing. So it's really quite different and it's called the Alzheimer's Prevention Initiative, so it's going to draw people who are interested in Alzheimer's prevention, and that's good. We think that calling it Brain Health Registry is going to attract a different kind of audience, a broader audience, and we think it may in the end get us larger numbers but who knows? The Trial Match, the Alzheimer's Association Trial Match is really not for everybody. Trial Match is for people who want to end up really specifically participating in clinical trials and usually the people who are going to sign up for that are people who are treatment-seeking, the people who think they have a problem and they're looking to join a clinical trial. And also when you join Trial Match, you are asked relatively little information, you're asked to provide your e-mail and then you'd be contacted about being in a trial. So it's extremely complementary, we're not competitive and we're not

profit-making so we're not competing with anybody we just want to help and if we can work more with these organizations or other organizations we'll be very happy to.

**George Vradenburg:** Great. Just as a reminder, if you have a question for Dr. Weiner press star 3. By pressing star 3 you'll be placed into a question queue and we'll get to you as soon as we can.

We do have an online question here from Tracy. What is the website to sign up? Tracy, we've mentioned but I'll repeat it, it's [BrainHealthRegistry.org](https://BrainHealthRegistry.org).

We have an online question as well from Ray Bonachea who said that he joined the Registry, answered all the questions, but there's no place to enter any special circumstances or information. He has a cochlear implant and cannot have MRI. It seems that would be important to you in assessing his availability or his utility in a clinical trial to know that. Is there a way to provide some supplementary specific information?

**Dr. Michael Weiner:** Well, first of all I want to thank Ray. That's a very good point and I know that some of my staff are on this call and they are probably writing that down right now. That's exactly the kind of comment we need. I agree we don't have anything like that now and that's something we need to think about and add.

I should expand on that, we need all kinds of input. We need questions, we need criticisms and we have a "Contact Us" feature to the website so people can do that and we take this all very seriously, we have somebody who looks every week at all of the comments and questions that come in and the staff discuss it. And we have improved the site a lot because of this feedback and we are working hard to make more improvements. We are just limited by our funding and our programming staff and so forth to enhance the site. We have a lot to do to make the site better and to add things, including for example feedback features. Currently when you register, you don't really get any feedback on your answers at all and people repeatedly ask for that. There's certain kinds of feedback we don't feel like we can give but we can give some and we're going to try to add that to the website in the coming months.

**George Vradenburg:** Great. If you liked Ray's last question, you're going to like this one too. Ray has an additional question. Can he have the test results sent to his primary care provider? And if so, how?

**Dr. Michael Weiner:** We are not set up to do that at this time. And that's again the kind of thing that we've been thinking about and we need to figure out how to do that. There are a lot of issues here, concerning privacy and our institutional review board. It's a very good point but I'm sorry at the moment we don't have that feature.

**George Vradenburg:** So we have a question here from someone on the telephone line, Meryl Comer, who has just written an extraordinary book called "[Slow Dancing with a Stranger](#)," about her experience as a caregiver. Meryl what is your question?

**Question:** Hi there. Thank you Mike, fascinating work that you're doing. Mike we know that there's a great angst of people around their brain, 60 million play Lumosity. Can you give us the pros and cons of the benefit of playing brain games as exercise?

**Dr. Michael Weiner:** Well first of all I should tell you that we have a partnership with Lumosity and some of the tests that we have on our website are Lumosity's and I really like the people at Lumosity, I think it's a great company. My knowledge of that field is that there is data suggesting that playing brain games and, including Lumosity games and other types of games, can lead to improvements in neuropsychological test performance. So if you've given some tests, and then you play games for a while and then you are given test again, you can improve your test scores. But it's very unclear how long lasting these effects are, whether playing these games really affects your functionality, and of course the really big question is if playing these games prevents you from having real cognitive decline and developing mild cognitive impairment, developing dementia. And nobody has an answer to that. It's a very important area for research, lots of people are working on it on the academic side and there are companies that are making various types of games. It's becoming a whole industry and Lumosity is an important player there. But I think that even if you look at Lumosity sites, they're very, very careful about the claims that they make. There are people who swear by these games and play them a lot and think it helps them and there's certainly no evidence that it's going to hurt you. But I think that the jury is really out in terms of what is the long-term effectiveness and it may very well be that the Brain Health Registry can help get these questions answered.

**George Vradenburg:** I have a question here from Mary Salter. Mary could you ask your question?

**Question:** This is my question, I'm not sure that my family and I are in the right place as far as the site and that's what I need to find from you. I have a very probably a different case than most people that are registered on your site. My family carries a PSEN1 gene, which is an early on-set Alzheimer's, we have lost six family members from the age of 37 to 45 with onset being in the mid 30's, six to seven years from onset to death. I'm do have two children that have tested positive for the PSEN1 gene. All three of mine are invested in a study at Washington University you might be aware of the [DIAN study](#) which is the Dominantly Inherited Alzheimer Network. So I'm not sure that my participating and my children participating in this Healthy Brain Registry is where we need to be? And I don't want to take up space or do anything that would stop somebody else from coming in here and maybe learning and getting more information that possibly will help them but that's not going to help me.

**Dr. Michael Weiner:** Well first of all, thank you and I'm sorry that your family has this problem. I know about the DIAN Study and in fact I'm on the Advisory Board of the DIAN Study and we have collaborations with John Morris and Randy Bateman in that very important study.

First of all I encourage you and all the members of your family to join the Brain Health Registry and we greatly value your data. We want everybody to join the Brain Health Registry, if it doesn't take too much of your time. We are having discussions with a number of large projects, including DIAN, about the possibility of using the Brain Health Registry to help them get better data, more data, and enroll more subjects and you can just imagine, cause you know, you're making all these visits to WashU or to some site and this is a big advantage of our website. I'll just be a little more general, people who are involved in research, where they might be going to Harvard once a year or may be going to Johns Hopkins once or twice a year and may be having brain scans at Berkeley. There are people, some of them on this call, who are involved already in research. But you know you only go to these places occasionally, once a

year, twice a year, maybe three or four times a year. The beauty of a website is that you can capture information at home.

**Question:** Right.

**Dr. Michael Weiner:** What's interesting is that many people have told me that they feel they do better on these tests when they take them at home on the website, than when they go into the clinic. And I found the same thing because I'm a subject at ADNI. If I go into the memory clinic and I've got some young psychometrist there who's giving me this test, I get kind of intimidated. I'm an older guy, you got this young person, I'm trying to remember these things and there is some anxiety associated with it. If I go home and I go to the Brain Health Registry and take the test, I'm sitting in my living room, I feel relaxed, and I think it's a better measure of my cognitive performance. So I think the Brain Health Registry is very complementary to studies like DIAN and we want to work with DIAN and other projects to find ways of helping them get more information to enhance their work.

**Question:** Okay. Then I guess we'll hang in here. And I agree with you, my children when they have to take the cognitive test they hate it. They hate being locked in that room. They are intimidated by it.

**Dr. Michael Weiner:** Though this is not a substitute for that. We need to have in-clinic tests but this provides additional information and they could be done more often. So I think that everybody on the call can kind of sense the value of this.

**Question:** Okay. All right. Thank you.

**George Vradenburg:** We have a streaming question here from PF. How anonymous is that. When a person registers on the website, they identified themselves as a caregiver and they wondered whether they would be in your system and how that would be used in potential studies?

I don't recall actually a question being asked about whether I was a caregiver or not but I'm curious is there a question regarding caregiving? Is there a different category of information relating to caregivers on your system?

**Dr. Michael Weiner:** Well at the moment, no. But whoever asked that question is very clever because this is very important. What we need to have is what we call caregiver, or maybe a better word because I don't consider my wife for example my caregiver, she may consider herself my caregiver, but we call it a study partner or informant. That is if you have a subject who is involved in research it's very useful to have information from an external source who's close to that subject. We call it an informant. And one of the things that we are planning to build is what we call an informant portal or an informant registration. So George, your wife could enroll as your informant and she would answer questions about you and then you could actually enroll as your wife's informant. So she can enroll as the subject, she can enroll as your informant, and vice versa. And this kind of information is gathered in all clinical trials. Just because somebody says, 'Oh I think I've got some memory problems.' That's what we called self-reported information but if the informant says, 'You know, I think that my husband over the last year there has really been a change and his memory is not what it was a year ago.' Now that's really

important. That's very, very vital information. At the moment we don't have a way to capture that but that's on our list, how to do that is complicated, involves privacy issues, consent issues, which questions to ask etc. etc. But it's of great interest to the pharmaceutical companies and other researchers and we're going to tackle that and hopefully have that available hopefully within a year but again, it depends on our resources.

**George Vradenburg:** Catherine Symons asked a question on the streaming side of our personality today. With a national registry is there a consensus among the professionals regarding the intake questions and how can therapists or others who actually evaluate and treat this population provide the input to you about whether the questions are the appropriate ones or whether there should be others added?

**Dr. Michael Weiner:** That's a very good question. So the way we decided what the questions would be is we began with ADNI. So [ADNI, the Alzheimer's Disease Neuroimaging Initiative](#), it's a huge project. We've got \$140 Million from NIH so far, we've enrolled 1,500 subjects. ADNI has a team of dozens and dozens of nationally recognized investigators who've put together this project and there is a whole set of questions that are asked every subject in ADNI. So we just started by using that. And in addition, we look around at other studies and picked up other questionnaires and added those so that's how we did it. Our sleep questions come from the [Pittsburgh Sleep Quality Index](#) and we have questions from the [MoCA](#), we have questions that are taken from all of these various standard instruments.

For people who are interested in providing suggestions and input, it can be done either by using the Brain Health Registry, 'contact us', click on the website and you can just send us an e-mail that way or you can e-mail me directly [michael.weiner@ucsf.edu](mailto:michael.weiner@ucsf.edu) and let me know. We're always looking for input and we make no claim to perfection and this is just the beginning. Let's face it, using the internet to recruit people, and assess them, and screen them, and monitor them longitudinally for all kinds of neuroscience studies just make sense. And we're trying to do it, we're experimenting. We're trying to find a better way to do it and we're just at the beginning of doing this and we've got a long way to go so we need input and we need help and we'd like as much help as possible.

**George Vradenburg:** I applaud your openness and I agree with you about the use of the internet, as I come from AOL, and about the need for version 1.0 and 2.0 and 3.0 over the course of the years there are constant improvements as a consequence of learning and getting feedback from people.

We have a question online from our streaming side from Mary Justice. She has read recently about people with Down syndrome having a very high, 100% chance, of getting Alzheimer's by age 40. How is Alzheimer's going to be studied with these people as subjects and I guess a related question goes to the earlier question which is, is this one of those additional pieces of information that you'd like to know about your registrants when they sign up to your Registry?

**Dr. Michael Weiner:** Well first of all the whole Down's story is extremely interesting from the scientific point of view and of course it's a sad story for people with Downs in their families that these people are developing early Alzheimer's disease. There's a whole group of scientists who are doing this as a whole big national project now that [Bill Mobley at University of California in San Diego](#) is heading. So that's a very important area I would love to encourage people with Down Syndrome to join the Brain Health

Registry, people with Downs and their families. I would love, when time and resources will permit, that we would have another module that would be aimed at determining whether people do have Downs. It's not currently there, it's something that we should be adding in the future. I would love to have an advertising campaign. I'd love to set up a national registry for Downs subjects and the Down's families using the Brain Health Registry. This is the kind of thing our website could do. We could have an advertising campaign, a marketing campaign to get people with Downs to join the Brain Health Registry and be followed longitudinally and that would help in many ways. We would get a lot of interesting data on them just from the Registry and also maybe some of these subjects would ultimately be interested in participating in clinical trials so having them in the Registry we'd be able to feed them to clinics.

So I think that the people who are listening can see the potential for this. You can do this for Downs, you can do this for traumatic brain injury, you can do this for depression, you can do this for people with family histories of Alzheimer's disease. There are lots of ways of marketing the site, getting people interested, we'd like everybody to join and we'd like to keep enhancing the site to capture more and more information.

**George Vradenburg:** I think we have time for one more question and I'm going to Marilyn Flint to ask her question from Bellingham, Washington.

**Question:** Hi. I've been researching Alzheimer's extensively because I lost both my husband and my mother to it.

**Dr. Michael Weiner:** I'm sorry.

**Question:** ...and I'm finding out that the brain desperately needs the essential fatty acids, the perfect balance of omega-3 and omega-6. We get it from mother's milk, but the only other foods that has that perfect balance is the oil from the industrial hemp seed, which doesn't have THC, it cannot make you high. And I've been studying this extensively and it's been studied all over the world in other countries but it's not reported on very much in this country even though they have patented the ingredients in the hemp plant and on the website it states that it does have benefits for Alzheimer's and other neurodegenerative diseases. I was wondering how we can get the word out in this country about the benefits that it has.

**Dr. Michael Weiner:** You know, I'm very interested in the whole omega-3 story, there has been a lot of work done on this. I wasn't aware that hemp oil had a particularly good balance, that's very good information to know. I think what's really needed is more good control trials, randomized trials where some people get it and some people are not given it demonstrating the long-term beneficial effects of this. I think that in the scientific community the jury is still out as to the benefit of taking additional omega-3's, DHA, and other types of supplements like that on the long-term cognitive health of people. So more work needs to be done, more good Science to demonstrate the benefits because if these things are shown to work then the world will go out. So thanks for your question.

**George Vradenburg:** Thank you very much, Michael for joining us today, for your commitment to this. Thanks for Lilly for supporting this.

If you are interested in receiving an e-mail from the Brain Health Registry with more information, please press 1 now or click "Yes" if you are listening online. We'll share your e-mail with Dr. Weiner so that he can e-mail you more information.

Thank you all for participating today. In about a week we will have a copy of this recording and a transcript on our website for you to share with your friends and we will send you a summary of this call as we send it to the other over a thousand people that have asked for a summary that we prepare.

As always, please stay on the line if you'd like to leave us a message with a question or comment. We're particularly interested in what you would like to discuss on future calls. So again thank you Dr. Weiner, thank you Eli Lilly, thank you all for joining us today, and have a good afternoon.

| **Dr. Michael Weiner:** Thank you George. Thank you USAAgainstAlzheimer's. Bye.