

NWX-HHS-AOA-1

**Moderator: Amy Wiatr-Rodriguez
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12:00 pm CT**

Coordinator: Welcome and thank you for standing by. At this time all participants are in a listen-only mode until the question-and-answer session of today's conference.

At that time you may press star 1 on your touchtone phone to ask a question. I would like to advise all parties that today's conference is being recorded if you have any objections you may disconnect at this time.

I will now like to turn the call over to Ms. Amy Wiatr-Rodriguez thank you, you may begin.

Amy Wiatr-Rodriguez : Great, thank you everyone for joining us today. I am Amy Wiatr-Rodriguez with the Administration on Aging within the Administration for Community Living, and I'll be moderating today's Webinar, "Updates on Alzheimer's disease research and resources," which is the first in the five part series.

Before I introduce our speakers, we have a few housekeeping announcements. First, if you have not done so please use the link included in your email confirmation to get on to WebEx so that you can not only follow along with

the slides as we go through them but also ask your questions when you have them through the chat feature.

If you don't have access to the link we emailed you, you can also go to www.webex.com, click on the attend the meeting button at the top of the page, and then enter the meeting number which is 668323478.

If you have any problems with getting into WebEx, please call WebEx technical support at 866-569-3239.

As the Operator mentioned all participants are in listen-only mode until the end when we have our Q&A session; however, we welcome your questions throughout the course of this Webinar, and there are two ways that you'll be able to do that -- one way in addition to the Q&A at the end but if you want to ask a question during our presentations, you can use the chat function in WebEx and as we as best we can as we take breaks after each presenter, we'll try to get to those question that are submitted through WebEx.

If there are any questions we can't answer during the course of the Webinar, we'll follow up to make sure that we get those questions answered.

And if you think of any questions after the Webinar you can also email them to us at amy.wiatr@acl.hhs.gov or to any of the email addresses that are included in the PowerPoint slides that are the basis for this Webinar.

As the Operator mentioned we're recording this Webinar and we will be posting the recording, the slides, and a transcript on the AOA Website at www.aoa.gov as soon as possible.

Our speakers today include Jane Tilly, Doctor of Public Health with the Office of Supportive and Caregivers Services in the Administration on Aging within the Administration for Community Living.

Nina Silverberg Ph.D., Assistant Director, the Alzheimer's Disease Center Program with the National Institute on Ageing.

Jennifer Martindale-Adams a Doctor of Education and Co-director with the Caregiver Center of the Memphis V.A. Medical Center.

David Parris, Senior Associate Director who's filling in for Ruth Drew of the Alzheimer's Association.

Mary Osborne, Program Manager with Eldercare Locator of n4a.

Jennifer Watson, Project Officer with the Alzheimer's Disease Education and Referral or ADEAR Center with the National Institute on Aging.

And we are also excited to have two special previously unannounced guest speakers; Reisa Sperling, M.D., Professor of Neurology at Harvard Medical School; Director, Center for Alzheimer's Research and Treatment at Brigham and Women's Hospital, and Harvard Aging Brain Study at Massachusetts General Hospital; as well as Melissa Gerald, Ph.D., Division of Behavioral and Social Research with NIA.

We are so pleased to have our wonderful speakers today and all of you joining us and so without any further ado at this point I'd like to turn it over to Jane Tilly with the Administration for Community Living to kickoff today's Webinar, Jane.

Jane Tilly: Thanks Amy and welcome to everybody. I guess I should say good afternoon for those of us on the eastern part of the country and probably still good morning to those of you on the west in the western part of the country.

I on behalf of the Administration for Community Living I'd like to thank you for attending this Webinar and hope you will attend the next four Webinars we have over the next few months.

I'm going to be talking to you about updates on ACL activities related to dementia capability, and I'm also going to be talking to you about and that involves implementation of Secretary Sebelius' National Alzheimer's Plan so I'm going to talk a little bit about the plan.

And talk to you a little bit about availability of previous Webinars we've done in this series in 2012.

So first I'm going to start off by talking about the goal of this we are now in the second year of our Webinar series. The goals you can see on the slide are to improve coordination of federal resources that are available for people with dementia and their family caregivers. And another important goal that's equally important is to encourage awareness of research participation opportunities broadly across the country.

This is as you may know a collaboration of the Administration for Community Living and the National Institutes of Health. It's in fulfillment of part of the Secretary's National Alzheimer's Plan.

We are in when we did the series the first series of Webinars in 2012 this was our inaugural effort to improve coordination of federal resources. And the Webinars featured a variety of presentations about resources from the

Administration on Aging which is part of ACL such as the Eldercare Locator and the National Alzheimer's Contact Center which is operated by the Alzheimer's Association. We featured those kinds of resources as well as the National Institute on Aging Funded Alzheimer's Disease Centers and the Alzheimer Disease Education and Referral Center.

I'm pleased to note that this effort, our collaborative effort between ACL and NIH, received and was recognized as a key innovation by Secretary Sebelius and also won the People's Choice Award for its success. And the success is basically we're connecting more individuals to the services provided through the Administration for Community Living and actually led to a 25% increase in perspective research participants in clinical trials related to dementia.

And the Webinar series we initiated in 2012 has continued to inspire collaborations at the state, local and grassroots levels. And if you look at the next slide you can see at the bottom of it that there is a link to the 2012 that link at the bottom of the slide which is entitled Webinar series calendar if you go to the link at the bottom you can get access to the 2012 series of Webinars that I was talking about and I want to make an announcement about our upcoming 2013 series.

Our second Webinar is going to focus on people with intellectual disabilities and dementia such as folks with Down syndrome that's on June 25th.

A month later we will have a Webinar on diverse populations that have an increased risk of having Alzheimer's disease that's on July 24th.

The fourth Webinar in our 2013 series is going to be in August and that will focus on people who get dementia before the age of 65.

And then the last Webinar to round out our 2013 series will be on advanced stages of dementia and palliative care as with the 2012 series that I spoke about earlier the shortly after each of the five Webinars in our 2013 series you will be able to get the slides and transcripts at the Website at the bottom of the slide.

Next I'm going to turn to on the next slide I'm going to turn to a little bit of background on the National Alzheimer's Project Act. I'm not going to go through all of the bullets here one by one but suffice it to say that this Act was signed in January 2011, Secretary Sebelius was immediately responsive to the legislation to the law and set up an advisory council that advised her about a National Alzheimer's plan and the Act required development of a plan and also part of the plan was to coordinate research and services across federal agencies which is what this ACL / NIH collaboration is responsive to.

Also the Project Act requires accelerating the development of treatments and that is not possible without participation in clinical trials.

And there are a number of other key components of the Act that you can see on that slide including improving early diagnosis of care and coordination of care and treatment.

If you go on to the next slide you can see the National Alzheimer's plan goals, and this is the Secretary's plan that was responsive to the National Alzheimer's Project Act. The plan has five goals which are to prevent and effectively treat Alzheimer's disease by 2025 and that's a key goal because that involves participation in research that can help find the prevention and treatments for Alzheimer's disease by that year, and that's a goal of the Secretary and President Obama.

Another goal is to optimize care quality and efficiency, expand supports for people with the disease in their families, and enhance public awareness and engagement. And again being aware of opportunities to participate in research and also understand services available to families is an important part of implementing the Secretary's plan.

And as you can see at the bottom of this slide that's entitled National Alzheimer's Plan goals you can look at the 2012 plan and its progress and implementing it at the Website at the end of that at the bottom of that slide.

We are anticipating the release of the 2013 National plan the Secretary's plan in the spring of this year, and the 2013 Webinar series is part of continuing to implement the Secretary's plan.

We expect that the 2013 plan will maintain the same goals. What will change is that we have implemented some of the 2012 plan goals and we've, we are planning on adding, excuse me, we have implemented some of the National plan's action steps from 2012. Those will be marked as completed in the forthcoming 2013 plan but we've also added new action steps, and you will by checking into the Website be able to see what the new 2013 plan looks like.

I want to move on to the next slide and talk about some of the outcomes that we've accomplished from the Secretary's 2012 plan.

As you can see one of the things we did on this was something that the National Institute on Aging led was to establish an international Alzheimer's disease research portfolio. And the purpose of that was to make sure that researchers and funders and consumers across both within the US and across the world understand what research is underway and in the various aspects of taking care of people with Alzheimer's disease and their caregivers.

The purpose is to make sure that investments are well coordinated and to encourage collaboration, to identify research gaps, and a very importantly in this era of tight funding, to reduce unnecessary duplication of effort.

And the IADRP will provide a way of starting the progress of research in Alzheimer's disease, and this is a user-friendly database. It's available at the Website on this slide in the first bullet.

Another important outcome from the Secretary's 2012 plan was that the National Institutes of Health did an analysis of assessment tools that could be used to assess a person's cognition in a variety of outpatient settings. They provided, the National Institute on Aging provided this analysis to the Centers for Medicare and Medicaid Services and they chose eight assessment tools to recommend to physicians and other primary care providers to use to determine whether or not someone may have cognitive impairment, and if they do one of the recommendations was that physicians if a cognitive impairment is recognized that practitioners rule out potential reversible causes of cognitive impairment such as depression. These are conditions that mimic cognitive impairment or dementia but actually have treatments available that might refer to them.

The third accomplishment for 2012 was led by the Administration for Community Living. We convened a specific population taskforce that looked at the special needs of three sub groups of people with dementia: those who acquired dementia before the age of 65, racial and ethnic minorities that are at an increased risk of having dementia, and also individuals with intellectual disabilities such as Down syndrome. And almost everyone who has Down syndrome if they by the time they reach their 50s or 60s most of them have acquired Alzheimer's disease.

We got a number of recommendations from key stakeholder groups and one of the key findings is that primary care practitioners who interact with these populations need to be aware about the increased risk of dementia and understand how to help their patients with dementia most effectively and that may mean acquiring additional training and education.

If you go on to the next slide that's entitled Translating Innovation to Impact, we have another 2012 accomplishment again led by ACL was the it's actually the I misspoke. This was a public private partnership it was led by the Alliance for Aging Research with funding from the MetLife Foundation in partnership with ACL.

What happened was there was a White Paper written that basically reviewed the known interventions and there have been quite a few of them in three different areas related to people with early interventions to help people with in the early stages of dementia interventions to help the caregivers of people with Alzheimer's disease and interventions that address care transitions.

That White Paper is available online at the link on this slide as well as a Webinar that presented the findings of the White Paper plus a the results of a meeting. The White Paper itself summarizes the interventions as well as recommendations from a meeting that was held to discuss the findings of the White Paper and I would -- anybody who is serving folks in the community with dementia and their caregivers, I would encourage you to take a look at that because there are some very valuable information.

And then the final accomplishment from 2012 that I wanted to talk to you about was a partnership between again, ACL, the Administration on Aging within the Administration for Community Living. This was a partnership

between AOA and the American Bar Association. And this slide addresses shows you where you can get information about the legal issues Webinar series.

And this was a four-part series; again it was called for in the Secretary's 2012 National Alzheimer's Plan. And the idea was to educate legal professionals as well as aging network professionals about a number of issues that are of key concern to folks with dementia and their caregivers.

And one is assessing a client's capacity to make decisions about their future when they have dementia. Another Webinar addressed advanced healthcare and financial planning. A lot of the decisions that need to be made for example, around bank accounts, durable power of attorney, different insurance options.

And then another Webinar addressed elder abuse, neglect and exploitation issues. All of these Webinars are available online at the link on the slide that you can see.

And then on the next slide just a little bit of a preview of the Secretary's 2013 National Alzheimer's Plan as I mentioned it's to be released in this spring hopefully within the next month.

As I mentioned the goals and the strategies are going are likely to be similar to the 2012 plan but the action steps we're, since we are making great progress in implementing the 2012 plan, the action steps in the 2013 plan are going to there are going to be additional action stuff.

You can find about all of this in one of two in ways. One is to periodically visit the National Alzheimer's Project Act Website which is listed on this

slide. Or you can join the Listserve for the National Alzheimer's Project Act and the instructions for doing that are in this slide.

And I would encourage everyone to stay tuned because we have a lot more work to be done in this area, and I would stay tuned to the new work and if you haven't made use of the work that's already been accomplished, I would encourage you to do that.

And that concludes my remarks Amy.

Amy Wiatr-Rodriguez : Great thank you so much, Jane.

Next we'll hear from Nina Silverberg with NIA who will update us on some of the many things going on in the world of Alzheimer's and dementia research, Nina.

Nina Silverberg: Hey Amy could you go on to the next slide. My name is Nina Silverberg. I work at the National Institute on Aging and our Division of Neuroscience where we do most of the work on the dementias of aging. You can go on to the next slide.

I apologize for not including my contact information but at the end of this entire Webinar will be a presentation on the Alzheimer's Disease Education and Referral Center which is connected to the National Institute on Aging. And if you need to you can reach me through that number.

So I'm going to mostly talk about the Alzheimer's Disease Centers. I'm one of two people at the National Institute on Aging who runs the Alzheimer's Disease Centers program and the first slide is just to give you a feel for where

they are across the country. We currently have 27 Alzheimer's Disease Centers funded by the NIA and there they are go on.

On the next slide you'll see some information about the primary functions of the Alzheimer's Disease Centers. They're mainly to characterize the participants in the clinical cores of the Centers. And they're followed annually and assess they're given all kinds of assessments, take many hours and they're seen every year. They're followed up with the idea of following them all the way through autopsy so that we have a better idea of how all those assessments relate to the pathology if any found in their brain.

So they're all the ones where it's possible followed up with neuropathology analysis. And each of the Centers has research projects affiliated with it some are funded through the Center but most are connected to the Center.

And another very important goal of the Alzheimer's Centers is to recruit participants into other clinical research including clinical trials. And they also provide infrastructure and data for large national studies. And here I've listed the National Alzheimer's Coordinating Center where all of the centers provide a uniform dataset. All the data from that is provided to the National Alzheimer's Coordinating Center and any researcher can apply to NACC to receive whatever data they're interested in and follow up with research.

The Centers also provide tissues and other biological material to the National Cell Repository for Alzheimer's Disease which is in Indiana.

And they also provide the infrastructure for the Alzheimer's Disease Cooperative Study which is a cooperative of more than 50 sites across the United States and Canada that runs clinical trials and you'll be hearing more about that momentarily from Dr. Reisa Sperling.

There's also the Alzheimer's Disease Genetics Consortium which is now an international consortium but the Centers have provided quite a bit of material and data to the genetics consortium.

And finally I've just looked at here's Alzheimer's Disease Neuroimaging Initiative which is an ongoing public private partnership to evaluate people who are potential participants or similar to participants in clinical trials to get a better understanding of the course of Alzheimer's disease starting prior to the development of the disease and going through all the way through mild cognitive impairment into Alzheimer's disease and following them for a bio-markers including imaging and other bio-fluids.

Next slide please. So here I've listed examples really from off the top of my head to give you a feel for the different focuses of the different centers. And really this is not at all an exhaustive list but gives you a really good idea of the different types of populations that different centers focus on.

So our Center at Northwestern has some work on English As a Second Language. We have some centers that have a good focus on rural populations because as you might imagine it's very difficult to perform assessments and to follow people so they've done at UT Southwestern at the University of Texas some work with telemedicine and some rural populations in Oregon and St. Louis.

I'm not going to go through all of these in detail but really the idea is to give you the feel for the different centers have a different focus and their different populations. And then also not just some of these under-represented groups that I've listed at the top but also specific populations, for example, in Kentucky they have a very large number of subjects that have no cognitive

impairment because we still have quite a bit to learn about bio-fluids and normal changes in aging that might occur in all the different types of assessments that we do and to learn more about those.

We have some that have gathered populations with Down syndrome with frontotemporal lobar degeneration, we have quite a few centers with that focus and now we've developed a module that some of them can add on to do specific research on that topic and that data will also be collected at NACC.

Next slide please. I was also asked to give an update about the Alzheimer's disease-related dementias. In 2012 we had a meeting that was titled, Alzheimer's Disease Summit that was part of the NACC plan. And in 2013 the National Institute of Neurological Disorders and Stroke organized this Alzheimer's Disease-Related Dementias Meeting which is also in service of the National Alzheimer's Project Act.

And at the link provides at the top you can see there they have the full agenda which I'm not going to go through but also available via video. I apologize for the siren that's from here.

Next slide please. I've summarized on the next couple of slides the agenda just to give you a feel for the areas covered. The types of dementia that were covered in this meeting were defined by the National Alzheimer's Project Act. So in addition to the different types of dementia the first session was on diagnosis because that's one of the primary problems that's been identified is that it's very difficult even for trained clinicians to diagnosis related dementias that are not Alzheimer's disease.

And most people we have found now have not only one but multiple forms sometimes. So that meeting covered Lewy body dementias, frontotemporal dementia, and other myopathies.

Next slide please. Vascular contributions to Alzheimer's disease and related dementias that session covered both how vascular contributions connect to Alzheimer's as well as to the other types of dementias.

And then finally the fifth session was on health disparities, and I'm proud to say that I helped organize that session, and it was I think very wide ranging. It's split into two sections: one on recruitment which is a major issue for health disparities populations particularly for the non-Alzheimer's dementias it's even more difficult. And then a real focus on the science of advancing treatment and prevention strategies among diverse populations.

And this is my last slide; I also want to mention that the National Institute of Child Health and Human Development as well as the National Institute of Neurological Disorders and Strokes and the National Institute on Aging in collaboration with Down Syndrome Research and Treatment Foundation and Research Down syndrome held a meeting April 16th and 17th. And the primary goal of that workshop was to develop a research agenda for advancing treatments for Alzheimer's disease and Down syndrome. And hopefully fairly soon we'll have a summary of that available to the public so I just wanted to make you aware of that.

And now I have the distinct pleasure of introducing Dr. Reisa Sperling who as Amy mentioned is a Professor of Neurology at Harvard Medical School. She's also the principal investigator on the NIA Fund at Harvard Ageing Brain Study as well as the Director of the Massachusetts Alzheimer's Center Outreach Corp and the Neuroimaging Program at Mass. General Hospital.

She served as the Chair of the NIA Alzheimer's Association Working Group to develop the criteria for preclinical Alzheimer's disease and she will serve as the Project Leader for the Alzheimer's Disease Cooperative Anti-Amyloid and Asymptomatic AD we're calling the A4 Trial which is the secondary prevention trial, Reisa.

Reisa Sperling: Thank you so much Nina and it's really a terrific opportunity to speak with you guys today.

So let me move right away to really discussing how we are changing the way people think about clinical trials in Alzheimer's disease. This really is a tremendously exciting time.

I'll start just by acknowledging my relationships with industry and also especially acknowledging the funding from the National Institute on Aging which has made this research possible.

Next slide. So one of the things I suspect I don't need to tell anyone on this Webinar is that we really do need to start to shift our approach to Alzheimer's disease clinical trials because the past decade's really been kind of tough in terms of successes in several trials. So ten large scale trials that are done at the stage of Alzheimer's disease dementia when people are already fairly impaired and there's wide spread nerve degenerating in the brain really have not been successful.

And our hope is that if we could intervene much earlier, even prior to the stage of dementia or symptoms at all, that we have a better chance of changing the clinical course.

There's a tremendous public health impact if we could even delay dementia by just five years. It's been suggested that this would decrease projected Medicare dementia costs by nearly 50% just by delaying dementia.

And when I look around at my colleagues and other fields where they've really had major successes in treatment, I see that they do this by really shifting their focus towards very early diagnosis and treatment and prevention. So if you think about cancer or stroke, or osteoporosis, HIV / AIDS, or diabetes, really we make most of our successes when we treat before symptoms are clinically manifested.

Next slide. So what I'm next going to show you here is this showing you that what we now think of a continuum of Alzheimer's disease and over the past two decades we've really run almost all of our clinical trials at the stage of dementia in the far bottom right corner.

It's been exciting over the past five to ten years there've been a few trials that have moved back up this trajectory towards the stage of Mild Cognitive Impairment or MCI which is sometimes referred to as prodromal stages of Alzheimer's disease.

And I think that this is a major success moving forward but ultimately I suspect if we really want to impact the course of this disease we have to move even earlier because we know even at the stage of MCI unfortunately there's already significant loss of nerve cells in key areas of the brain that are important for memory.

So a lot of our work over the past few years is really focused on moving us back up to this trajectory to this stage referred to now as preclinical Alzheimer's disease. And these are individuals who have evidence of

Alzheimer's disease changes in their brain evidence of pathology but don't yet have any symptoms.

And of course, at this stage of preclinical Alzheimer's disease it's very difficult to tell apart from normal aging or changes in the brain in typical aging that are not early Alzheimer's disease but fortunately we have some real exciting biomarkers and tools to help us get there.

Next slide. So next I'm going to be showing you some evidence of one of the I think revolutions in the field which is the ability to detect one of the pathologies in Alzheimer's disease now during life, and this is PET amyloid imaging.

I'm just showing you some data from our studies here, but I'll show you some other data in a moment. The majority of patients with Alzheimer's disease dementia although not all of them already have very elevated levels of amyloid plaques in their brain and we can now pick this up on PET imaging during life.

And you can see in the column marked Alzheimer's Disease or AD there that these areas that are pink and red all around the cortex of the brain that are very important for thinking, and memory, and concentration are already full of amyloid plaques.

The majority of normal older people called NC or Normal Controls here do not have a lot of amyloid in their brain. But as we started to do these studies, we found that about 30% of these normal individuals already do have evidence of amyloid in their brain and they further more, they have it in exactly the same anatomic distribution that you see at the stage of Alzheimer's disease dementia.

Next slide. So just lest you think that this is something strange about the people older people up here at Harvard because we may be a bit strange, I wanted to show you some of the data from three other very large studies looking at older individuals with amyloid imaging -- the Australia study AIBL, the Mayo Clinic Study, and also Washington University.

And really this is one of the pieces of data that's been the most remarkably consistent, that about 30% of older individuals have evidence of amyloid in their brain before they have any symptoms at all.

Next slide. This work that we've done in older individuals is very much supported by what's been seen in autosomal dominant in these genetic rare populations who are at 100% risk for Alzheimer's disease dementia if they carry one of these new mutations. This is work from the DIAN Study which Nina had mentioned on one of her slides and very similarly you can see that amyloid begins to accumulate 15 to 20 years before the age of symptom onset in these individuals.

This work has also been shown in the Alzheimer's Prevention Initiative in another cohort with a genetic risk.

Next slide. So the real question here is can we use these methods, click next slide, first, if you click again I think you'll get to the step, perfect, right there.

So I'm showing you here a curve of prevalence of Alzheimer's disease dementia. These are from epidemiologic studies and as you can see this increases exponentially with age.

Next slide click. Here is a shown in green is the likelihood of having plaques in your brain at an autopsy study if you're still normal but you happen to be hit by a bus and had an autopsy, and you can see that that curve is very similar although it's shifted over.

One more click. Now I'm going to show you in these blue dots the likelihood of being amyloid positive on a PET scan so it does appear we really are able to pick up this early form of pathology at the same rate we can see it at autopsy but now during life.

Now we don't yet know whether these blue dots will turn into red diamonds and develop symptoms of Alzheimer's disease dementia.

Next slide but what you can see here is that we estimate one more click that it is about 15 years between the time that you develop amyloid plaques and you get to the stage of Alzheimer's disease dementia.

Now for me this is a glass half full because what an incredible opportunity to intervene in these individuals. Next slide.

So this has led to the idea of moving towards secondary prevention clinical trials. Right now again we do our trials at the stage of MCI or dementia which might be thought of as tertiary prevention.

Of course, we all want primary prevention we want to be able to find something safe enough to put in the drinking water of everybody over the age of 21 and prevent the formation of Alzheimer's pathology in the brain altogether. But those trials are a little more challenging, and we don't have a drug ready for that yet.

What we do have and what's so exciting that will be happening over the next year are these secondary prevention trials where we try to delay the progression of cognitive impairment in people who already have evidence of Alzheimer's processes beginning in their brain. Next slide.

So what we'll be doing I'm going to just tell you very briefly about several trials funded by the NIH that are starting this year. The first is the Alzheimer's Prevention Initiative this was part of a special program that was announced at the NIA Summit last year. This will be in one of these rare forms of Alzheimer's disease genetics lead driven that often affects people in their 40s.

Similarly the Dominantly Inherited Alzheimer's Network of DIAN is aimed at these rare genetic forms of Alzheimer's disease as well and that will be run out of Wausau.

And finally I'm going to spend my last minute talking about the A4 trial that Nina mentioned the Anti-Amyloid Treatment in Asymptomatic Alzheimer's disease. Next slide.

So this trial, the A4 trial, is really aimed at the much more common risk factor for Alzheimer's disease. Next slide if you can pop that one up, which is people who are unfortunately entering the age of risk for Alzheimer's disease which is above age 65.

And this will be a secondary prevention trial in individuals who are identified on PET amyloid imaging as having evidence of amyloid but who are still normal. And we'll treat them with an anti-amyloid treatment in this case Solanezumab one of the monoclonal antibodies for three years.

We know that's not a long enough trial to see whether we ultimately prevent dementia but it is long enough to see if we can bend that curve up of very early cognitive decline. And importantly the study also has a disclosure of amyloid status ethics sub study and we're trying to develop new methods that will make the next set of prevention trials more efficient. Next slide.

So I'm just showing you a schematic here of why we need your help of everyone on this call. In order to do this study we'll screen over 10,000 individuals, and we'll be getting PET scans in a large number to find the 1000 who will enter this trial.

And we've required that one out of every five individuals in A4 be from an underrepresented minority population. So we know this is a challenge, and we really need your help in getting out there with a very broad outreach, but I think the study has a chance to really teach us about the natural history and hopefully again bend that curve. And then the last slide I think next slide.

There are many other trials starting I've highlighted the prevention trials but there are multiple trials that are ongoing at the stage of mild cognitive impairment and mild Alzheimer's disease dementia with many other therapies not just amyloid mechanisms. And as the speakers before me emphasized that what we really need is help in rapidly recruiting these trials.

We think the we have successful drugs and really the bottleneck is getting these trials out there to test them as soon as possible. So next slide is just showing you some of the resources that you can go to for information across the government as well as in private foundations in terms of getting information especially about the prevention trials but lots of other clinical trial opportunities coming up.

So I'll end there and I'm happy to answer questions now or at the end if needed. Thanks so much.

Nina Silverberg: Amy do we have any questions at the movement or should we move on?

Amy Wiatr-Rodriguez : I don't have any questions right now; you can go ahead.

Nina Silverberg: Okay thank you so much Reisa that was very informative. And our next speaker I'm pleased to invite Dr. Melissa Gerald who is also at the National Institute on Aging. She's in our Division of Behavioral and Social Research. She joined in February of this year, and I already got her roped into doing this.

((Crosstalk))

Melissa Gerald: Well thank you very much for including me in this.

Nina Silverberg: Before that she was a Scientific Review Officer at the Center for Scientific Review, CSR. And she's going to be telling us about the portfolio that NIA funds on caregiving research Amy...

((Crosstalk))

Melissa Gerald: Okay so thank you very much. Yes, as it was said that I am in the Division of Behavioral and Social Research. We're one of five divisions at the National Institute on Aging.

If I could have the first slide please. And today I'm going to be talking about some of the AD and AD related dementia caregiving studies that we are currently supporting and that we have recently supported.

If I could have the next slide please, thank you. So we at the Division of Behavioral and Social Research support social, behavioral, economic research and research training on the processes of aging at both the individual's and societal level. And we foster cross-disciplinary research at multi-levels from genetic to cross-national comparative research and at stages from basic through translational.

As you can see in this slide here, we have two branches, the Individual Behavioral Processes and the Population and Social Processes Branch and some of the research that we supported is highlighted here.

We've also invested heavily in developing some key longitudinal publically available data resources such as the Health and Retirement Study, the National Health and Aging Trends Study, the Wisconsin Longitudinal Study, the Midlife Development in the United States, and the Panel Study of Income Dynamics.

BSR has a great interest in supporting projects that leverage values from these investments by either expanding the scope or the direction of ongoing BSR sponsored projects related to family caregiving or by conducting secondary analysis of data from these existing datasets. If we can have the next slide.

I'm going to highlight some of the previous studies that have been done and the current studies in AD caregiving. But you can see here in this slide some of the key areas that we've focused on. We've done a lot of research on the impact of AD caregiving. There's compelling evidence from several BSR funded projects that demonstrates that Alzheimer's and dementia caregiving can come at a cost to the health and wellbeing of the caregiver.

And there's a growing body of evidence that has even implicated dementia family caregiving as a risk factor for health. Compared to non-caregivers, men and women who provide care to a spouse with dementia face an increased risk of depression, high levels of stress hormones and insulin, they report more infectious illness episodes, they have impaired immune function with poor immune responses to different viruses and vaccines, their wounds heal more slowly, and they're at greater risk for developing hypertension and coronary heart disease.

Moreover, a prospective longitudinal study found that the relative risk for all cause mortality among strained caregivers was 63% higher than non-care giving controls.

Indeed caregiver stress represents one of the few naturalistic models to study the biological concomitants of chronic uncontrollable stress in humans. And we're supporting projects that are seeking to uncover the pathways and mechanisms behind these diverse health risks associated with caregiving and other chronic stressors. Let me highlight a few examples.

(Igor Grant) is following-up on findings that caregivers exhibit greater depressive symptoms, worse sleep efficiency and higher basal norepinephrine and to understand why older caregivers are at greater risk for developing cardiovascular disease, in his efforts to identify major markers of psychobiological stress related caregiving and to provide direct evidence of caregiving associated cardiovascular damage.

In a series of studies amongst others, (Elissa Epel) and (Janice Kiecolt Glaser)'s research has shown that caregiving stress can result in increased production of pro-inflammatory cytokines which play a central role in the range of age related diseases and that AD caregiving can reduce telomere

length; telomeres are caps at the end of our chromosomes that protect our DNA and which shorten as we age but when too short, may lead to cell death.

(Steve Zarit) found that caregiving is associated with biological changes in the body's stress response that can have long-term implications for health. And his recent research published last week online was on the use of adult day services for dementia care. And he showed that dementia caregivers were exposed to fewer care related stressors on days that they used adult day services care and they reported more positive experiences despite reporting more non-care stressors in their day. And adult day services use lowered anger and reduced the impact of non-care stressors on depressive symptoms, and that's pretty exciting findings with implications that the use of these adult day services may provide protection against some of the effects of chronic stress associated with caregiving.

Although I've mentioned several studies that have looked at the negative impact of AD caregiving, I should also point out that we've supported research and are supporting research that is looking at how the impact of caregiving for Alzheimer's family members can affect different people differently.

We've supported research such as that conducted by (Peggy Dilworth Anderson) which has shown that cultural beliefs and values, as in her studies of African American caregivers, can also contribute to health outcome and compound the effects.

Moreover, notwithstanding this discussion of negative consequences, we are supporting research by (Lisa Fredman) to seek out mechanisms that can explain why some caregivers experience improvements in health as a function of dementia caregiving. And so for some people there can be benefits, and she's seeking to identify some of those mechanisms.

We're also supporting research that is looking at the changing demographic and economic trends of AD caregiving. (Michael Hurd)'s recent analysis derived from samples collected in the Health and Retirement Study shows that the US spends more on dementia care than heart disease or cancer. And the high cost associated with Alzheimer's disease and related dementias is attributed primarily to institutional and home-based long-term caregiving.

If you can turn to the -- I think we might have skipped this slide on AD caregiving and health...we can continue.

AD caregiving research has also been devoted to development of interventions. BSR is committed to the development of effective caregiving interventions to promote the quality of caregiving as well as health and wellbeing outcomes for AD care recipients and caregivers.

Our next speakers will be discussing the NINR cosponsored Resources for Enhancing Alzheimer's Caregiver Health, REACH Project, which at its inception, examined feasibility and outcomes to promote promising intervention approaches for enhancing family caregiving for Alzheimer's disease and related disorders but here's the brief overview of some of the other AD related intervention projects that we support.

For example, (Susan Mitchell)'s been investigating in ways of improving palliative care of advanced dementia such as through Advanced Care Planning interventions.

Brent Mausbach is evaluating the efficacy of a brief Behavioral Activation Treatment called the "Pleasant Events Program" for reducing biological cardiovascular disease risk indicators and spousal Alzheimer's caregivers.

We have (Thomas Jakob) who's developing a tool, as part of an Internet based training program, to educate family caregivers about preserving the functional ability of people with Alzheimer's disease.

And other initiated studies are developing intervention strategies to improve communication among individuals who are in the early stage of dementia and family caregivers in a project led by (Elia Femia) and amongst physicians, patients, and family caregivers about a diagnosis of a dementia in (Brian Carpenter)'s project. And to improve sleep and dementia caregivers in (Meredith Rose)'s, and (John Zeisel) has created interactive plays to increase engagement and improve positive affect in persons with dementia and their family members.

If I could have the next slide please. And as we're well aware, there are many critical gaps in understanding and addressing the caregiving needs of individuals suffering from Alzheimer's disease and those of their formal and informal family caregivers. BSR would like to encourage projects that can ultimately move evidence-based research findings towards the development of new interventions, programs, policies, practices, and tools that can be used to promote the health and well-being of AD care recipients and caregivers.

To address the unmet needs of AD care giving, here are some of the knowledge gaps that we want to focus on: on characterizing AD caregiving demographic profile, specifically by improving the understanding of the identity of AD caregivers and by operationalizing caregiving, as there is considerable variation in how caregiving is defined for individuals and amongst others, (Eliseo Perez-Stable) and (Gina Moreno-John)'s BSR-funded work underscores the need to pay attention to cultural and ethnic differences

in understanding caregiving and in developing culturally sensitive dementia caregiver interventions.

Our population has greatly changed and we need to understand - have a better understanding of the economic impact to families and society, to forecast our future needs. Last year we issued a Program Announcement, "Estimating the Economic Cost of Alzheimer's Disease and Related Dementias", which continues till 2015, and this funding opportunity encourages research which would develop reliable estimates of the economic cost of Alzheimer's disease and related dementias and to project future cost in the coming decades. Not only the direct and indirect cost to public and private healthcare payers, but also those costs faced by families and other informal caregivers, as well as the labor market costs from reduced productivity or labor force participation.

We need to continue studies to investigate how AD caregiving impacts the health and well-being of the caregiver, particularly, in relation to identifying the mechanisms and the processes involved. And we need to better understand how caregiving needs change as a function of time and with AD severity.

There are also gaps in the availability of evidence-based interventions for AD caregiving and we're interested in filling this gap, with respect to monitoring, surveillance, and communication technological interventions, such as: decision aides, safety technologies, alert systems, and reminders, and ways we can use technology to promote the health and well-being of AD care recipients and caregivers.

If you can turn to the last slide. BSR is committed to filling some of these gaps. And if you want to hear more about our Division or some of our sponsored research, take a look at past publications and workshops, our centers, and data resources and datasets that are available for analyses, and

different funding opportunities, here's the Web site. These are hyperlink text that you can click on, to get them or you can contact me directly by emailing me at my email address here. Thank you very much.

Amy Wiatr-Rodriguez: Wonderful. Thank you so much (Nina). (Unintelligible) we do have a couple of questions that come in on the web chat in Q&A feature. One question from (Brittany) came and this can be of the people who presented so far or any of the other presenters coming up, whoever wants to take this. But (Brittany) is wondering the percentage of people with dementia versus those who would be considered to be normal aging.

Nina Silverberg: Is Reisa still on? She may have had to leave. I think she did. Okay. Well I would say that...

Reisa Sperling: Yes I'm on, sorry.

Amy Wiatr-Rodriguez: You're a better person to answer that than I am.

Woman: Oh sorry. Can you repeat that question for me because I just caught the very end of it?

Amy Wiatr-Rodriguez: Sure. The question was regarding the percentage of people who have dementia versus those who are considered to be aging normally.

Reisa Sperling: Well 1 out of every 9 individuals is said to have Alzheimer's disease dementia in this age group, but really that curve increases exponentially as I showed you. So once you're over age 85 it's thought to be 1 in 3 or even 1 in 2 who have dementia and the majority of that is still Alzheimer's disease. So again at all comers it's about 1 in 8 or 9 of older individuals have dementia as opposed to normal aging.

Amy Wiatr-Rodriguez: Great. Thanks so much. Another question has come in from (Jody) and she's wondering if there's any research or interventions or anything to address the homeless population who may have dementia.

Nina Silverberg: (I)'m (Nina). Not to my knowledge. However there are some speculations and unfortunately right now it's just that that some proportion of especially people over say 40/50 who are homeless, some proportion of those people may have frontotemporal dementia which has quite a few behavioral symptoms.

And if you're interested in more details about that, you can look at University of California at San Francisco has a really informative Web site if you have access to the web which I guess you do if you're on the webinar which has even videos included that shows some people that are known to have frontotemporal dementia doing things like searching through garbage cans and, you know, drinking sodas that they find that a normal cognition person wouldn't be thought to be doing.

Again we don't really know the incidence of mental health issues in the homeless population so that's kind of the best answer I can give right now. To my knowledge there haven't been specific studies on dementia in the homeless population, although I suspect there are studies showing the age of the homeless population, but I'm not quite aware of those statistics.

Amy Wiatr-Rodriguez: All right great. One last comment came in from (Pat). I'm wondering if any of the speakers would like to comment or share. She's saying that, "My interactions with caregivers have led me to wonder if a major way to reduce stress is maybe to somehow help them to develop more techniques to be in and understand the world of the person with Alzheimer's

such as Best Friends and Montessori approaches.” Would anyone like to comment on that?

Melissa Gerald: I’m not aware of any studies that are going on right now that are using any of these approaches. There are other approaches that are being used - medication types of interventions that are and perhaps some of them more non-traditional types of methods, but I’m not aware of any of those approaches.

Nina Silverberg: We do have a couple. I would suggest that maybe we can provide some background papers on the Web site following the webinar...

Amy Wiatr-Rodriguez: Okay.

Nina Silverberg: ...that can provide some of the answers to some of these questions.

Amy Wiatr-Rodriguez: Okay great. And we’ll do just one more question coming in because I know we still have more speakers to go. Just one last question from (Rayna) was any advancements in non-pharmacological multi-modal interventions for prevention of Alzheimer’s or for delayed onset such as walking, social engagement, and reminiscence therapies.

Melissa Gerald: Shall I answer that one Nina or...

Nina Silverberg: Yes please.

Melissa Gerald: Okay sure. So actually there’s quite a lot of work going on in this way. So one is a lot of work going on in exercise. Some studies - (Burns) in the Midwest as well as the ADCS is doing an exercise trial in mild cognitive impairment, and I know there are other studies really looking at aerobic exercise. There are some smaller intervention trials that have looked, as you said, at multi-modal

which I think is very exciting, combining social and intellectual stimulation with physical exercise, and I think is a really important area to pursue. There's also lots of studies going on with the diet. Mediterranean Diet and also blueberries and currently with Resveratrol, one of the chemicals that's in grapes and red wine.

Amy Wiatr-Rodriguez: All right wonderful. All right now we do have some other questions coming in, but we're going to move on in the interest of time and make sure we get to our other presenters. So at this point I'd like to turn it over to Jennifer Martindale-Adams from the Memphis VA Medical Center to talk about another critical aspect of research which is that of translating the research into practice. So Jennifer? Jennifer are you on mute? Jennifer?

Coordinator: I am showing Jennifer's line is disconnected.

Amy Wiatr-Rodriguez: Oh okay.

Coordinator: One moment. Let me see if she's dialed back in. Jennifer if you are in the conference - oh, I do see her here. Is it Jennifer Watson?

Amy Wiatr-Rodriguez: No, Jennifer Martindale-Adams.

Coordinator: Thank you. One moment while I scan the conference.

Amy Wiatr-Rodriguez: Okay. Maybe while we're doing that another question came in from (Margaret) on how much money has been spent on research. If anyone has an exact dollar...

((Crosstalk))

Woman: Not enough. Currently I can only speak to the NIH and maybe (Nina) can speak, but it's about \$454 million per year on Alzheimer's disease research in NIH budget which is less than a tenth of what we spend on cancer. And although there are monies in private foundations compared to the cost of this disease which is over \$200 billion in care cost, it's estimated that we spend less than a percent and maybe even less than 1/2% of that on research so we've got to shift that balance.

Nina Silverberg: This is (Nina). As part of the executive branch I'm not allowed to comment on that. However I would refer you to the Alzheimer's Association Web site that has a lot of information about that topic. Also I can refer you to as (Jane) mentions IARDP, our Alzheimer's disease research portfolio which you can search by topic area within Alzheimer's disease.

The full thing covers - the full database covers all of Alzheimer's disease research and all of the institutions - funding instructions that we have incorporated thus far. We're still trying to get more included. But in the meantime it'll give you a feel for how much is funded, and you can sort by funding agency.

Amy Wiatr-Rodriguez: All right. Let me just check in with our operator and see if we've been able to get Jennifer Martindale-Adams on the line.

Jennifer Martindale-Adams: I am here.

Amy Wiatr-Rodriguez: Oh wonderful. Would you like to go ahead Jennifer?

Jennifer Martindale-Adams: I would. Thank you for allowing me to talk about our program. I'm the Co-Director of the Caregiver Center at the Memphis VA and I'm going to

take a few minutes to talk about our translation of research and we've been able to do this into the VA system.

On the next slide you'll see the history of REACH. I think that REACH is the perfect example of research implementation because the REACH VA program has followed a trajectory from feasibility studies to national implementation. The National Institute on Aging and the National Institute of Nursing Research funded REACH 1 in 1995. It was the first national program to evaluate behavioral interventions for dementia caregivers and six feasibility studies evaluated a wide variety of intervention approaches.

We looked at what worked in each of these six studies and were lucky enough to get funded for REACH 2. So based on the REACH 1 findings, NIA and NINR funded REACH 2. It was the first national randomized clinical trial to evaluate behavioral dementia caregiver intervention and diverse caregivers, and it was implemented in five sites.

The multi-component six-month REACH 2 intervention provided education, support, and skills building in home and by phone. Intervention caregivers compared as a control group showed significant improvement in burden, depression, health, self-care, social support, and management of patient behaviors and gained one extra hour per day not spent in care giving tasks.

The results were promising, and all involved in REACH 2 wanted to move into the community. We were lucky enough to receive funding from the VA to do a translation of REACH 2 into the VA. REACH VA was the first national clinical translation of a proven behavioral intervention for dementia caregivers running from September 2007 through August 2009.

We had very similar results as REACH 2. From the eight caregivers, the intervention has been shown to decrease burden, depressive symptoms, the impact of depressive symptoms on daily life, the potential for abuse as measured by caregiving frustration, and the number of traveling dementia behavior-related issues reported.

Caregivers reported an extra hour that was decreased per day in the time they spent caregiving and a decrease of two hours per day in the amount of time on duty.

Beginning in February 2011 we began the REACH VA program. It may appear at the end of the (arrow), but it continues to be a journey. And I'm going to tell you about the sustainability of the program and changes that we have to made to the program and some of our outreach programs.

On the next slide you see the main components of the REACH 2 intervention. When we implemented the REACH VA translation in the implementation phase, we stuck to the original REACH 2 protocol and intervention as close as possible.

Like REACH 2 the six-month REACH VA intervention would include nine one-hour individual home sessions, and three half hour telephone sessions, and five one-hour monthly telephone support group sessions. The intervention included education, support, and skills training to address five (unintelligible) risk areas: safety, social support, problem behaviors, depression, and caregiver health.

On the next slide you'll see questions that came up during the translation and on into implementation. We were told by the experts and translations to stick

to the REACH 2 protocol as close as possible, and we have done that since 2007, but we hit some road blocks.

The VA staff are adding the carryover programs onto existing workloads. The implementation was time limited, so the buy in was time limited. There were concerns about the length of the intervention from the field. We looked over the program evaluations, and we could see that the model needed flexibility to work in the VA. We took into consideration all of the concerns and comments from the VA staff and the fact that some of our colleagues have reduced the REACH 2 model with similar results.

As REACH 2, we wanted a model that can be used in the VA without stress to the staff and that will allow the flexibility that is needed by staff and caregivers, so we decided to make changes. The one thing that we knew was that we had to keep the core components, the ones from REACH 1 and REACH 2 that were proven.

On the next slide I have the new REACH VA structure that we implemented June 2012 to help us with the sustainability of the program. When we sent out the new materials, we had five colleges to call and check on it. We had spent so much time telling them they had to do 12 sessions and they wanted to make sure we were okay with the changes, and I must say it was hard. But here is the new program, and I think it's wonderful.

The program includes an active intervention phase with four core sessions with a caregiver over two to three months. These four sessions incorporate the core evidence-based components of REACH VA: education, safety, problem solving, med-management, and stress reduction. It is still based on a risk assessment. REACH VA focuses on the critical skills to empower the caregiver. The new model will allow for additional sessions based on

caregiver need, desires, and goal attainment as well as the intervention (as to) clinical judgment.

If problems arise, there is a maintenance phase where additional problems or stress issues can be addressed with a caregiver. The REACH VA program can be delivered face-to-face that would be in the home or facility or over the telephone.

On the next slide you can see that topics covered in the telephone support groups. The only difference to our telephone support groups is that it can now be a standalone intervention or the intervention and the group leader can still work together, but it is not required.

There's still questions that come up. (Unintelligible) next slide. There are still questions that came up. Can we do it face-to-face instead of by the telephone and all the answers are yes. We're working right now on a model that would work in our community living centers, which is our nursing homes, that we could train the interventionist to work with staff and with the caregivers so that everyone has the same care plan and are doing the same model with the patients to help reduce stress for everyone involved.

On the next slide we are very excited about the model. The staff is very excited. Our goals are still the same. Our new motto is we want to reach more caregivers and this new structure has done just that. Our caregivers served - the numbers of our caregivers served begin to increase in just the first month of the new model.

Next slide. On the next slide REACH is focused and efficient. REACH is standardized and this helps to maximize staff and caregiver time. For the convenience of our staff scripts are provided, and they've got lines for each

encounter that they have with the caregivers. They are specifically designed to maintain program (unintelligible) and assist in effective communication with a caregiver. In order to facilitate a personal connection with a caregiver, the staff is encouraged to become familiar with the contents of the script and not read the scripts verbatim.

And we really want to focus on maximizing the staff time so that when they're there, the caregiver knows what to expect and were able to move through and get the information to them in a timely manner.

On the next slide is what we do here at the Caregiver Center. We provide the training and materials. Everyone that is an interventionist or group leader will get all the manuals they need. They're designed to be grabbed and go. Each interventionist or group leader and caregiver gets the caregiver notebook. The notebook was written at a fifth grade reading level with educational information and practical strategies that can be personalized for the caregiver with 30 behavioral and 18 stress and coping topics.

As of this month we've trained 90 VA sites and 251 staff members. We tripled the number of caregivers services as the new model wasn't placed. We're still evaluating the new model. Since it's only been a year, we've taken a quick peek of our results and they're looking very similar to the previous (unintelligible) so we're very excited about that.

On the next slide REACH VA has branched out in spinal cord injury. We have the same training as the dementia model with a (unintelligible) ID specific caregiver notebook. We'll still in pilot work with the REACH VA (SEID) and (YA) has allowed us to have a community outreach.

We mentioned a little bit earlier about the NAPA plan. And we have a terrific opportunity to partner with the Indian Health Service to offer REACH VA for family caregivers of Native veterans with dementias and we have trained staff from the Oklahoma Alzheimer's Association and staff from the Oklahoma Healthy Aging Initiative. And on the next slide I want to thank you for your time and you can contact us if you have any questions.

Amy Wiatr-Rodriguez: Great. Thank you so much Jennifer. And for everyone on the call, you can hear how much is going on and you might be thinking well how do I keep up with all this information and where do I find the resources to help the individuals and families that many of us serve so I'll just briefly mention two federally supported sources of information.

As you can see on the slide right now Alzheimers.gov is one source that individuals can turn to and it's a portal to the resources that we are featuring on this webinar and more. So you can see the, you know, lower right-hand corner you can see links to some of the things that we're talking about today.

Additionally I just want to mention one other Web site, longtermcare.gov which recently has refreshed the information on its Web site and it's directed towards consumers who are looking to plan ahead to help them understand long-term options.

But next up to give even more detailed information to us on some of the questions that people with Alzheimer's disease and other dementias and their family members and friends face is David Parris who directs the ACL funded National Alzheimer's Contact Center. So I'm going to turn it over to David.
David?

David Parrish: Thank you very much Amy. We can go to the next slide, the one on expanding your reach. I just want to talk about some of the smorgasbord of services offered through the Alzheimer's Association. Next slide.

That which I am most proud of and I think is kind of the crown - the jewel in our crown is our 800 number which is available 24 hours, 7 days a week, 365 days a year. And as Amy mentioned, we have had the privilege of being funded during the past decade by the Administration on Aging and Administration for Community Living and we have been able to through the funding serve thousands of families in the time of need.

We are available 24/7 and we offer not only information referral services, but we also offer care consultation. So at any given time of the day you can call the 800 number and request to speak with a care consultant. These are Master's levels clinicians with a background in clinical social work. Some of them in nursing as well as others clinical psychology who are available to provide emotional support as well as care planning resources and tools for caregivers and persons early in the stage of dementia. Next slide please.

Oh before I move off of the call center, I do want to emphasize also I'm very proud of this. We have increased our staffing. We've almost doubled in size during the past three years and now 25% or a quarter of our staff are fluent bilingual Spanish. We also have one who's bilingual Mandarin and two who are bilingual Korean. We also in addition at any given time of the day offer a language line service where language interpretation is available for persons in over 200 various languages.

The next slide, what I'm going to emphasize very quickly are some of the resources on the ALZ.org Web site. One of those which I think really, really is premium is the Caregiver Center. Within this are numerous links to pamphlets

to videos and to on hands tools that allow a caregiver to find resources for personal care, safety issues, and I'm going to highlight a few of these things within the Caregiver Center. Next slide please.

One of the resources is ALZConnected. This is actually a social network that's available 24 hours, 7 days a week for persons already diagnosed with the disease as well as for those who have interest in Alzheimer's care or are actually providing hands on care. There are public and private groups. There are chat rooms. There are message boards and all these are maintained by staff members of the Alzheimer's Association. Many of us within the 24-hour contact center as well as a team of ongoing peer volunteers who are persons who have provided on hands caregiving over a decade and have an expertise in Alzheimer's disease. Next slide.

Another tool on the Caregiver Center is the Alzheimer's Navigator. This is a series of questionnaires which allow individuals who are providing care for persons with Alzheimer's to create a personal care plan and will link them as well to information and local support resources. Next slide.

Also there's the Alzheimer's care team calendar. Now this is an updated version of something we used to offer called Lots of Helping Hands. What this is is a password protected calendar which allows individuals within a family or in a network of friends and neighbors to assist in the care of a person with dementia. It allows you to actually schedule appointments, tell family when you would be available for instance to provide rides, meals, this sort of thing. So it's a terrific service. The next slide please.

Also on our Web site is the community resource finder. This is a comprehensive service that allows you by entering your local zip code as well as your city and state to actually search for resources within your community.

Such things as adult daycare programs, skilled nursing facilities, any classes and seminars that may be occurring within your area as well as support groups and other services provided by the association.

Another service that's provided on here is an actual list of definitions of each of these types of services as well as tips on how to locate a good care facility, questions to ask about when choosing adult daycare as well as in home care providers. Next slide please.

Also we feature on the Web site numerous and there's about 15 of these altogether eLearning classes and these can be taken at your own convenience any time of the day. These are online courses that are embedded with videos, interviews, and with people who are actually living with the disease, people who have had to do legal and financial planning as well as one on kids and teenagers where actual interviews with teenagers who are living with an adult with Alzheimer's disease to discuss their experience as well as their coping mechanisms. Next slide please.

Also within the Web site we have two separate portals. One that features services and are resources available in several Asian languages as well as our Spanish portal which you can download a number of materials in Spanish. Next slide please.

Also within the Caregiver Center, there is a dementia and driving resource center. And what is here are safety tips as well as and let's focus on this slide are there are four separate videos that you can watch that demonstrate how to have a conversation with a person who has dementia and may no longer be able to drive or should not drive. And what's interesting here we have taken four various approaches to having that conversation. Next slide please.

Also there is caregiver online training. One of these is the (unintelligible) which is actually a certification program which will assist someone who for instance needs to do the CNA training, but it is also something that can be utilized by in-home caregivers discussing - learning how to move a person with dementia, how to communicate effectively and so forth. Next slide please.

Also featured on the Web site is our Virtual Library. This is access to all the materials of the Greenfield Research Library plus it also allows you to actually communicate with the research librarian through chat, email, and phone and have access not only to her knowledge and knowledge about research but also to link into other resources.

And finally TrialMatch which was mentioned earlier is our online as well as you can use it through the call center 800 number to assist in creating profiles and encourage clinical trial registration. And the last slide just puts up the 800 number which is available 24/7 as well as the link to our Web site. Thank you so much Amy.

Amy Wiatr-Rodriguez: Great. Thanks David. We're going to move right on to Mary Osborne with the Eldercare Locator. I do apologize, it looks like we're going to be running over a little bit but we will try to get through all of the slides and info that we have today. So go ahead Mary.

Mary Osborne: Good afternoon everyone. I'm sure most of you are familiar with the Eldercare Locator. We've been around 20 years now. For those that are not, I'll be very brief in my presentation here. Feel free if you have any questions to contact me later. Next slide.

There's two components to the Eldercare Locator. There's the call center and there is our Web site. On this slide you see it's our 1-800 number. The call center is open Monday through Friday 9:00 am to 8:00 pm. We have information specialists and Master level social workers on taking calls during these times.

We also have an after hours service and through this service you can actually find out what's your local agency information is and if the agency is open you can be connected. We also have bilingual staff. We have a language line, and we have enhanced services for those that need more information about topics such as transportation needs, long-term care questions, caregiver resources, if there's any concerns about elder abuse or any other complex situation. Next slide.

This is a sample of our web page, our home page and as you can see it has a searchable database. Lots of resources and tools are available through the Web site. One thing that is very confusing about this page is that you can search by location or topic and not both. Many visitors come to this site kind of look through it. If they have questions, they have an opportunity to chat with us or to email us at any time. Next slide.

This is a sample of the listing when you actually are searching by location where you put in your zip code and/or your city and state. And it gives all the information about those local home and community-based agencies that you might be looking for to help, you know, caregivers looking for services.

Also we get a lot of calls from professionals looking for what may be available to help, you know, their clients. It gives lots of information about describing definitions, services that that particular area the zip codes covered.

It'll give you a map. It also gives you the link to that agency's Web site. Next slide.

If you want to search by topic, you want more information this is an example of that page. It gives you the brief definition. Also gives you many links. On this particular one for caregiver of course it's linking to the Alzheimer's Association. It also has publications to tip sheets available. All these you can download. You can print out. Next slide.

These are some of the brochures that we offer. These are available. You can download them and print them out from the Web site or you can call us. You can order them online. You know, they're free for bulk orders and we get many of those. We just ask with some help with the shipping of it, but we have a lot more titles than this and they're available for you. Next slide.

This is just our social media page that we put postings on Facebook all the time. A lot of links to resources, community information, studies, things that are going on and this is very helpful for professionals. Next slide.

And I've run through that pretty quickly, but as I said if you have any more questions or concerns or anything that you would want to contact and get more information about feel free to call me. Thank you.

Amy Wiatr-Rodriguez: Thanks so much Mary. And my apologies to everyone on the line, we're going a little bit late. But hopefully Jennifer if you're still on and able to go over the information of the Alzheimer's Disease Education and Referral Center. We will have it available on a recorded version of the webinar as well as the slides and audio will be available for everyone even if people are unable to stay past. And apologies for running over, but Jennifer will you be able to go ahead?

Jennifer Watson: Sure. No problem. Thanks Mary for being really speedy and I will try to follow suit. Hi everybody, I am Jennifer Watson. I'm the Project Officer for the NIA Alzheimer's Disease Education and Referral Center and as my earlier colleagues (Nina) and others spoke about NIA is the lead federal agency for Alzheimer's research.

And Congress created Alzheimer's Disease Education and Referral Center in 1990 as (unintelligible) how to compile, archive, and disseminate information about Alzheimer's disease and particularly about Alzheimer's disease research for people with AD in their families, health professionals, and the public.

So we have lots of information and materials on our Web site and in print publications and social media, etcetera, to inform the public and others about Alzheimer's type research. So we focus on helping our audiences find answers about Alzheimer's disease. We also have a toll-free number. It is not 24/7, but it's Monday through Friday 8:30 to 5:00 and our Web site is obviously available 24/7.

We have free publications that you can use to provide at health fairs or other events through the Aging Network or organizations. We would be happy to supply those for your use. And you'll see as we go through the slide presentation some of the topic areas that I invite you and encourage you to really visit our Web site to get the full picture. Next slide.

So this again is the home page of our Web site. As you can see on the right-hand side we're featuring news and highlights about Alzheimer's disease research. Midway through the blue buttons on the right-hand side we have a listing of all the Alzheimer's disease research centers.

So for example our speaker Dr. Reisa Sperling is at the one at Harvard. We have 26 others across the country. It's helpful for folks to be able to access those with research centers that may be in their communities. And the button right below that is our clinical trials listing service so. And I would just draw your attention to the fact that we're now on Twitter and we hope you will follow us. Next slide please.

This is just a sample of some of the topic area pages. We've broken up our information into key information areas that we know users want to get quick snapshots of basic information, publications, and where the research is. So again I encourage you to explore our Web site. Next slide.

In particular we have developed a fair amount of information and publications and materials on care giving. You'll see we have a free guide called Caring For a Person with Alzheimer's Disease that is available and has been terrifically popular.

It was developed by the Rush Alzheimer's Disease in Chicago and we're really proud to distribute it widely and make it available. We've also broken it up into tip sheets and we're moving that into ePublication format so it will be available for people on their Kindles or eReaders of other sorts. Next slide.

I just also wanted to know that we have some information available about other dementias including frontotemporal dementias. Later this year we're going to launch a booklet on Lewy Body dementia, so we are broadening our base of dementias information. Next slide.

And here again is just where you can find our listing of publications that you can order online and have both copies available for events, etcetera. Next slide.

I wanted to point you to our clinical trial listing. This is a subset of the trials that are available in clinicaltrials.gov. We try to make them a little bit more user friendly, but they're searchable by location, by eligibility criteria, by drugs tested. So we're trying to feature those that are part of the Alzheimer's Disease Cooperative Study and NIA funds as well as industry trials all across the US.

So we've also broadened that to include trials related mild cognitive impairment and some other dementia trials as well. So you can either look at that online or we also through our call center have phone support for helping folks find trials that might be local to their area. Next slide.

This is just information about clinicaltrials.gov which I hope a lot of you know about already which is just the basic clinical trials mega database at NIA that provides comprehensive information about almost all clinical trials. Next slide.

One other resource I wanted to make sure you knew about is NIH has been working on efforts to raise awareness about participating in clinical trials. They've launched a Web site, [Clinical Research Trials and You](http://ClinicalResearchTrialsandYou.org), and it has great video testimonials from both participants and research and researchers themselves talking about why they participate in it and a lot of those are really helpful for people to understand what it means to participate in a clinical trial. So I would recommend that to you as well. Next slide.

And finally one last NIH sponsored resource is ResearchMatch.org. This is an effort to try and match researchers and their trials with people who are interested in participating in research of all sorts. So it's a low threshold. You just go to the Web site and put in very basic information about yourself and

then if research studies come up through this network they will contact you to see if you would be interested in participating. So we're exploring ways to work more closely with ResearchMatch.

I think it's a great addition to a lot of efforts that are happening to raise awareness about clinical trials and participating in research along with TrialMatch and many of the other research centers and registries that are happening. So I am optimistic that all these efforts together will encourage people to participate in research about brain health, about Alzheimer's disease, and help move us along. Next slide.

And finally here is our contact information for the ADEAR Center and as (Nina) mentioned you can either or both of us through the email here or by calling the toll-free number. Thanks.

Amy Wiatr-Rodriguez: Great. Thank you so much Jennifer and thank you to all of our speakers for today. I know that we're over time which is something that we did not want to do, but as you can see there's just so much information. So many questions to be answered and so much interest in all these topics. I'm wondering we do, you know, I'm looking we still do have some people logged on and so I'm wondering if we could open it up just for maybe one or two questions from on the phone since we did promise people the ability to do that. So operator would you be able to see if there are any questions coming in from the phone line?

Coordinator: Absolutely. We will now begin the question-and-answer session. If you would like to ask a question, please press star 1, unmute your phone, and record your name clearly. I will require your name to introduce your question. If you need to withdraw your question press star 2. Again to ask a question, please press

star 1. It will take a few moments for the questions to come through. Please stand by.

Amy Wiatr-Rodriguez: Great. And while we're waiting for that queue to come together, (Tara) had asked a question on what is the economic cost of Alzheimer's disease. And I'm wondering if any of our panelists would like to respond to that.

Woman: We actually just had a research finding recently and see if I can pull it up and answer that.

Amy Wiatr-Rodriguez: I'm guessing it's a big number. All right. And while we wait for that another question came in from (Brittany) asking about mental health and Alzheimer's disease and she's heard that depression and anxiety history puts people at higher risk and she's wondering if research supports or denies that.

Woman: What is the question again?

Amy Wiatr-Rodriguez: That people with a history of depression or anxiety have a higher risk of Alzheimer's disease and she's wondering if the research supports or denies that.

Woman: I think there is a fair amount of research that links depression and the risk for dementia.

(Nina): Yes that's correct. I don't have the exact statistics, but depression is both one of the early symptom of Alzheimer's disease and maybe other dementias as well as a risk factor for dementia. And I think there is quite a bit of research on this, and so we don't have a definitive answer in terms of what the risk is

and how it relates to the early symptoms of dementia. I think it's quite difficult to tease that apart.

Woman: And back to the cost question. There was a research finding that came out in April that said dementia care costs \$215 billion. I don't know if that was exactly the question, but I would be happy to send links to folks.

Amy Wiatr-Rodriguez: Okay.

David Parrish: Hey Amy, this is David. In terms of the cost of the healthcare long-term care and hospice care in the 2013 Alzheimer's disease specs and figures book, they refer to it as really close to what was just shared as \$203 billion for 2013 they project and by the year 2050, \$1.2 trillion. There's really a comprehensive discussion of the cost on page 41 in the 2013 Alzheimer's disease facts and figures which you can download on the ALZ.org Web site.

Amy Wiatr-Rodriguez: Okay great. Let me check in with (Sheila), our operator, to see if there are any questions on the phone line.

Coordinator: Yes. Our first question comes from (Neisha Rhodes). Go ahead your line is open.

(Neisha Rhodes): Hi. Good afternoon. Thank you all so much for the presentation. This was very helpful information. My question was regarding the - someone was talking about kind of looking at research on caregivers and possibly reducing those stressors by operationalizing caregiver techniques. I don't know if that speaker is still on the line, but I kind of wanted to, you know, to enhance on that theory.

Melissa Gerald: I was - this is (Melissa) who mentioned about operationalizing actually is the definition of what constitutes caregiving.

(Neisha Rhodes): Okay.

Melissa Gerald: There's lots of individuals that don't identify themselves as caregivers even though they may be (even devoting) the lion share of the caregiving. In terms of operationalizing interventions, that's another struggle that we're faced with is being able to even conduct comparative effectiveness trials for some of these interventions. And so there are a lot of refinements that must be done for, you know, for assessments of interventions and the design of them.

(Neisha Rhodes): Okay I see. Okay, thank you.

Melissa Gerald: You're welcome.

Coordinator: And as a reminder, please press star 1 on your phone and record your name if you have a question. One moment please.

Amy Wiatr-Rodriguez: Okay. We might take one more question from the phone line. Let me just - while we're doing that let me just show the last slide that we have here just noting that registration for Webinar number 3 which is the one on disparities, diversity, and dementia is now open. And you can still register for Webinar number 2 which is on intellectual and developmental disabilities and dementia and other webinars will open about two months in advance of each so, but those are the next two that are available right now.

As a reminder the slides, audio, and transcript for this webinar today will be available at the link the link that's listed there and you'll need to give us about a week or so for us to get all of the information and to post it there.

Unfortunately due to the size of the documents, it makes emailing to individuals very difficult and challenging. But what we will do is have an email go out to all people who registered once the materials are posted so that you'll know that you can go and access them and you'll have a direct link that will show you where to get to that information.

And then I know several of you have mentioned that other people were watching and, you know, with you who didn't register and how will they know. You can just forward that email on to them whenever you receive it so that they know they can also access it. And you can share it with all, you know, anyone else too to let them know that the materials are, you know, they're available and posted free and publicly available so that, you know, anyone can access them. So let me just check in and see if we have any more - one more question from the phone lines.

Coordinator: We have no further questions by phone at this time.

Amy Wiatr-Rodriguez: Okay wonderful. Well again my apologies for going over. But again thank you everyone for participating and thank you especially to our speakers. This has been wonderful. If you do have any further questions, suggestions, or feedback on this webinar it's very helpful for us to know to make sure that we're meeting your needs, you can email me at amy.wiatr@acl.hhs.gov and we want to thank you for that. So thank you for joining us. We look forward to having you with us in future events and this concludes today's webinar. Thank you.

Woman: Thanks Amy.

Woman: Thank you Amy.

Amy Wiatr-Rodriguez: Thanks. Bye-bye everyone.

Woman: Bye-bye.

Coordinator: That concludes today's conference.

Woman: Bye. Thank you.

Coordinator: Thank you for participating. You may disconnect at this time.

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