Moderator: Hello and welcome to public health live the third Thursday breakfast broadcast. I'll be your moderator today. Before we get started, I would like to ask that you fill out your online evaluation at the end of the web cast. Your feedback is helpful in planning future programs. We encourage you to let us know what topics are of interest to you. We will be taking your questions throughout the hour by phone. The toll free number is (800)452-0662. We will also be taking questions by e-mail. Please e-mail us at any time throughout the hour. Additionally, the school of Public Health would like to remind you of the new companion guide for the Public Health Live Program. The guide can be found on our website phlive.org. We'll provide guidance, discussion points and learning activities for those looking to enhance their learning. For persons with experience with our program, there is a section in the guide asking for audience feedback for how we can improve this product. We look forward to receiving your fax, e-mail and comments for suggestions.

Moderator: Today's program is Dementia Update, a new national plan for autism disease, research care and services. Our guest is David Hoffmann, the Bureau Director for the Office of Health Insurance Programs at the New York State Department of Health. Thank you so much for being here Dave.

Dave Hoffman: Thank you. It's a pleasure having you here. Today's topic is such an important and far reaching topic that I think we would be helpful in we started off by looking at a video produced by the Alzheimer's association that will give us an introduction to the scope of the problem we are facing. [Video]

Moderator: What a powerful video certainly some alarming numbers. David looks like we've got a lot to talk about today. Lot of ground to cover for the information we can cover today. It seems like the Alzheimer's Association is a great resource for the information noted in the video.

Dave Hoffman: The Alzheimer's Association is a terrific resource both for data and caregivers. The best way to reach them is to reach them on their web page.

Moderator: Terrific. Dave one of the things you'll be talking about today is some of the costs associated with treating Alzheimer's and the cost incurred by caregivers. Can you tell us about some of these costs?

Dave Hoffman: Absolutely, the bottom line is that the significant number that we saw in the short video there, $200 billion, but what makes up that number is also very important. In some senses, it's easier to measure the healthcare cost, the cost to insurers, to Medicaid to Medicare. But the out-of-pocket expenses to caregivers and business are significant. The cost to absenteeism and pre-absenteeism and the caregiver cost. We have a hard time quantifying.

Moderator: I also understand that a person having Alzheimer's significantly increases the cost associated with Medicaid and Medicare payments. Is that correct?

Dave Hoffman: If we look at the numbers on the slide, it's easy to see the diagnosis of dementia, the Alzheimer's disease, in and of itself is a predictor of significant increases in healthcare costs. This has a dramatic impact on people's health and their ability to manage their health.

Moderator: Dave a plan for our audience why Alzheimer's is such a cost driver? We really got to try to get a grasp of that.

Dave Hoffman: Alzheimer's is a cost driver for many reasons, primarily it's an expensive condition to manage and treat itself and it impacts both the caregivers and the person with the disease, ability to manage all of their
other conditions. We know that most people with Alzheimer’s have one or more serious conditions. Dementia complicates their ability to manage their condition. As senior with diabetes and Alzheimer’s cost Medicare 81% more without Alzheimer’s. This results in more hospitalization, fewer preventive services being provided and more serious complications. Things like hypertension and other heart disease, diabetes, cancer and arthritis are all harder to manage when someone has dementia. It results more in serious complications.

Moderator: Clearly, Dave, am I correct in saying this is a major concern? The number of people with the disease is actually growing? Absolutely, the number is growing. Some of that has to do with our aging population but also it’s a change in the way our healthcare community is dealing with dementia. There’s a growing awareness of the importance early diagnosis and the benefits of early diagnosis. What does a current Alzheimer’s landscape look like?

Dave Hoffman: Well, there’s some scary numbers here Joel. About 5.4 million people are living with this condition. Most of them, 5.2 million, are over the age of 65 but more than 200,000 are under the age of 65 and they have what’s referred to a younger onset version of the disease. Among people 65 and older, 1 out of 8 has Alzheimer’s. Nearly half of people over age 85 have Alzheimer’s. Every 68 seconds, as we saw in that video, someone develops Alzheimer’s. By 2050 that number, every 33 second.

Moderator: Those are absolutely astounding numbers. It’s incredible to think that beyond those suffering from the disease, there’s also such a huge impact for those that care for them. Can you talk to us about that?

Dave Hoffman: Sure, that’s over 15 million people who provide care for people with Alzheimer’s provide over 15 billion hours of unpaid care every year. If we wanted to quantify that in terms of dollars, it would be $210 billion. Additionally, being a caregiver for someone with dementia takes its toll on the caregiver as well in terms of their health and their mental health. The Alzheimer’s association estimates an additional $9 billion in healthcare cost associated with being a caregiver. This is for many reasons, the impact on physical and mental health happens. The risk for chronic conditions goes up. It happens because they lack time for physical activity. They lack time to ensure they have proper nutrition. They have less time and energy to avoid tobacco. The kind of the common risk factors that we think about for other chronic conditions and all of these things, the time constraints, the stress, both physical and financial stress and isolation really take their toll on caregivers.

Moderator: This disease is actually impacting and affecting a tremendous amount of people isn’t it?

Dave Hoffman: Yes, it is. When we think about this 15 million plus group of caregivers as we saw. If these were the residents of the imaginary state of dementia, it would be the fifth largest state in the country. These people are wrestling day and night with the challenges that are both hard to understand and hard to address. Often while handling their own health and other needs. These individuals are often an aging spouse with their own health challenges, dealing with the emotional loss associated with dementia or adult children caring for a parent with dementia while parenting their own children. Sometimes we even see children and adolescents as caregivers for an older relative. Every situation is unique. But as you can see from these examples, nothing is easy.

Moderator: Yes, so it’s evident that Alzheimer’s is widespread and impacting many people. What can you tell us about the disease itself Dave? Some people may still think that Alzheimer’s is just a disease that effects memory for example?

Dave Hoffman: That’s a pretty common assumption; that’ because memory is the first symptom that tends to appear. Alzheimer’s is the most common form of dementia. It represents about 80% of dementia. It impacts
mental ability and later in the process physical function, enough to interfere with daily life. Memory is usually the first core mental function where we notice the change. But that's followed by communication and language, ability to focus and pay attention, reasoning and judgment, and visual perception. At least two of these areas must be impacted for a diagnosis of dementia. Alzheimer’s is also fatal. As you see in the slide, it's the sixth leading cause of death. We all understand that for many people with dementia, the cause of death maybe listed for somebody else like pneumonia or stroke.

Moderator: I see. Dave, has there been any progress made in decreasing the incidents of Alzheimer’s death? It seems that we've made progress with many other leading causes in death. Where are we with this?

Dave Hoffman: We've had some great success addressing a number of conditions. Unfortunately, this is an area where the numbers are going in the wrong direction. The only positive of this is we're seeing the condition get a lot more attention both nationally and internationally. In March, the World Health Organization issued a new report Dementia, A Public Health Priority.

Moderator: Now, you've clearly laid out the landscape for us. What I'm wondering is, now because the nature of this disease, I would imagine that there are even greater implications for those who live alone. Is that true?

Dave Hoffman: It is true. The Alzheimer’s Association this year issued a special report as part of their annual publication of facts and figures estimating that of 800,000 people, 1 out of 7 people with Alzheimer’s disease live alone. Up to half of these people don't have an identified caregiver. I'm really glad that the Alzheimer’s Association focused on this population this year. They brought to light a situation that's pretty scary. I imagine this huge number of people trying to live life lacking million of the tools. Lacking many of the tools that you and I have.

Moderator: Dave can you share with us the details about the people who tend to live alone?

Dave Hoffman: Yes, these people tend to be older and female and less cognitively impaired. They manage thing like managing their money, shopping, and household chores and importantly managing medications. Remember this is a population of people frequently who have other chronic conditions and it's important for them to take their prescribed medications on schedule but given the dementia, that's hard to do. These deficiencies and practical activities that most of us take for granted every day, result if a real risk to these people and the people around them.

Moderator: Let's talk about that obviously these folks would be at a greater risk for some things. Can you talk to us about that?

Dave Hoffman: Sure, they are at a greater risk for malnutrition, untreated medical conditions, inadequate clothing or housing. Falls. I want to stress falls because that's frequently our reason for hospitalization. That's an avoidable hospitalization. Wandering away from home, unattended, accidental death, more frequent hospital stays and longer hospital stays. Higher per person outpatient costs but the list here doesn't tell the whole story. Often the items on this list serve to multiply the impact of other items on the list. A person who's malnourished can of a more severe impact from untreated medical conditions. Both of those can lead to falls or more hospital stays. You can see that everything here relates to the whole person and their risks. We need to think about the basics-- promoting health, maintaining health and safety. There aren't any easy answers to address this population of people living alone. But it's really good that the conversation has begun.
Moderator: Absolutely! I love the point that you made. I just want to underscore this -- focusing on the whole person -- every aspect of that being. Dave, what kinds of advanced planning can be done to help prepare a person who lives alone?

Dave Hoffman: First of all, early identification is essential. Advanced planning is critical. It has to be comprehensive planning. It has to happen early in the stage of the disease so the person with the disease can fully participate while they have the capacity to do so in making decisions about their own living situation and their life. They can help build their care team, they can make legal and financial plans. Care consultations can be very helpful to people who live alone. They can receive counseling, financing, long-term care planning, advanced directives to drive their healthcare and receive assessments of potential safety threats. We know that planning can make a difference for these people, but it needs to be comprehensive. It needs to recognize the progressive nature of dementia. The more planning that can happen early, the better for the person with the disease for any caregivers that they have and for healthcare providers that work with them.

Moderator: It seems so overwhelming. Just to be clear, once the initial diagnosis is made, that is the beginning of the advance planning so to speak.

Dave Hoffman: It should be. Absolutely that's correct. That should be the trigger for advanced planning for legal issues, for financial issues for healthcare issues, for housing issues and putting together a care team that predict my -- predictably that need to be in place.

Moderator: A comprehensive care team! Now that we know a bit more about what individuals can do, let's take a look at the bigger picture if you will Dave. How does the funding for Alzheimer’s research look? Where are we with that?

Dave Hoffman: Well, we're not where we could be. When we look at these comparison numbers for every $28,000 in Medicare and Medicaid spending, the National Institutes of Health, federal agency that oversees most federally funded researches spends $100 on Alzheimer’s research. This year the CDC will spend only $2 million to address dementia. Nationally we've got an issue of scale here. These numbers kind of speak for themselves. One of the difficulties that policy makers have had historically in understanding dementia is that unlike some other conditions, the people most in need are often not able to speak for themselves. Support groups like the Alzheimer’s association have started to make a change in that area but there's need for more.

Moderator: Absolutely, we've made inroads in programs such as that program today take a role so to speak in the advocacy movement. Would you agree with that?

Dave Hoffman: Definitely. The more people who are aware, the better off we'll all be.

Moderator: Absolutely, I agree with you. So clearly, we need more funding for Alzheimer’s research. This situation even caught the attention our president who made it a top priority. Can you talk to us about that today?

Dave Hoffman: Absolutely, we were very excited a year ago when President Obama issued his vision statement on the National Alzheimer’s Project Act which passed Congress early last year and he signed into law indicating that it's an important challenge but as an important challenge, it's one that the Federal government is ready to take a leadership role in. Important, because the President made this statement and signed this law, agencies across the federal government have become engaged. That's an important consideration.
Moderator: An important consideration indeed. Dave give us some more information if you will on the national Alzheimer’s project act? What are some of its purposes?

Dave Hoffman: Well, some of the purposes are to create and maintain and integrate a national plan. I will talk more about that in a minute. To coordinate and research and services across all federal agencies. To accelerate the development of treatments to prevent, haul or reverse the disease and to improve early diagnosis in coordination of care and treatment - importantly, this is a national plan and not a federal plan. It's not a plan for federal agencies to implement on their own. We all need to work together.

Moderator: Does the act also focus or have a purpose for racial and minority groups as well?

Dave Hoffman: Absolutely, this is really important. The goals are to improve outcomes for ethnic and racial minority populations at higher risks. We know that African-Americans are proportionally twice as likely to have dementia. Hispanics are 1.5 times as likely to have dementia. We don't know exactly why. These are important questions for us to ask. Additionally, the plan calls for us to coordinate internationally to fight Alzheimer’s. It’s not an American problem; it’s a human problem. We will be burying our head in the sand if we didn't realize other countries were wrestling with this issue and spending resources on research there too. Also the act called for the creation of an advisory council to review and comment on the national plan and its implementation. Dave, who’s guiding the work that's being done by the project?

Dave Hoffman: Dr. Ronald Peterson is chairing the council that I just mentioned. He's from the mayo clinic. He's a well-respected leader in this field. Every key federal agency with a role here has a seat at the table. Both the department of Health And Human Services, which is in the lead, the Department of Defense, the National Science Foundation and The Department of Veteran’s Affairs. The Veterans Health System is one of the primary providers of care to people with dementia.

Moderator: This is good news. Looks like an all hands on deck approach.

Dave Hoffman: It really is.

Moderator: I understand there was proposals to invest $156 million on Alzheimer’s research, what can you tell us about that?

Dave Hoffman: Just an old review! This investment was designed to take immediate action without waiting for congress and support for the national plan to increase funding at the NIH, the National Institutes of Health, immediately by $50 million during this year. This is already under way. Then to sustain and grow Alzheimer’s research investment in the federal, fiscal year 2013 budget by $80 million beginning on October 1st. It's important to know that congress hasn't acted on that proposal yet. It's important that we understand the need for many types of research, for new medicines, but also for ways to identify the disease early, any kind of preventive strategies that we can come up with and very importantly, research on supporting caregivers and how to do that best.

Moderator: Well, what I'm wondering also, does it also take into consideration supporting family and providers and educating the communities at large?

Dave Hoffman: There are some resources that are dedicated to that. If we look at the proposal, there's $26 million. This next proposal in the federal budget for education and outreach $82 million, outreach, $6 million
it’s really important that healthcare providers understand Alzheimer’s disease and dementia and how to work with people. Support for people with Alzheimer’s disease and caregivers, $10.5 million and improved data collection and analysis, $1.3 million. My observation here would be as I mentioned a few minutes ago, we really talking about the wrong scale. I read last night that one super pac spent $8.2 million in one weekend in one state on election advertising, $8.2 million can be spent in a weekend, but that’s the annual budget to educate Americans about this important condition. I make that comparison because I think it puts it into perspective. Tell us about the sub subcommittees and thorough role.

Dave Hoffman: Growing research seems to be just common sense. I’ve had the honor to chair the group focused on long term services and support and I’m here to tell you that the caregiver members of this group have added tremendous perspective and knowledge to the discussion.

Moderator: Absolutely! I not at the head of the table, they really got to be right there and I’m certain their presence is valued. Tell us how the direct plan was developed?

Dave Hoffman: As with many government processes, getting members appointed to the council took some time but the federal government got a jump start on this. We formed an interagency work group to the advisory council and they started with an inventory of what the federal government had been doing related to dementia across all agencies. Work today addresses the current program serving people with Alzheimer’s and their caregiver’s improvements to those program that might be possible.

Moderator: Now is it a federal plan?

Dave Hoffman: Importantly, it's not just a federal plan. It is a federal plan but it's really a national plan with goals for the federal government but goals for state government and the private sector as well. Dementia is not something we can address exclusively with federal government activity. We need to harness the resources of outside groups and we all need to work together. This national plan includes activities that are immediate actions, near term actions and longer range goals. It requires the engagement of both public and private stakeholders. The path forward will be contention on resources and contingent on collaboration. The research summit that was held by NIH in May to focus on Alzheimer’s disease, called on researchers to work together and collaborate in ways they haven’t in the past to share knowledge and progress to accelerate the process.

Moderator: What are the principles behind the national plan?

Dave Hoffman: The principles are very basic. To optimize existing resources to improve and coordinate ongoing activities, we can’t afford to misuse limited dollars to support public, private partnership and consultation with the advisory council and acknowledging that we need to work together. We really need a new paradigm, a new reality in the way we look at Alzheimer’s disease. We’ve talked in the past about Alzheimer’s disease about a title wave that was approaching us. It’s here.

Moderator: Absolutely. There’s no question about that. What about the specific goal of the plan Dave?

Dave Hoffman: The specific goals of the plan are ambitious. To prevent and effectively treat Alzheimer’s disease by 2025. To optimize care, quality efficiently and to track progress and drive improvement. As I said, these are ambitious goals. Secretary Sebelius and the White House have compared this to President’s Kennedy goal to put a person on the moon. It’s important to note that while these are ambitious, they are also reachable goals. We need to push ourselves to achieve them. Ambitious goals are good. Particularly in this
instance and we've made some very significant inroads but we can't stop now. We've got to push on to yield results from all of our good work.

Moderator: You said it. Definitely, each goal has several strategies in place to help ensure that this is accomplished. Can you tell us about the first goal and its strategies?

Dave Hoffman: Yes. Preventing and effect verily treating Alzheimer’s disease by 2025 is going to take significant action, identifying research priorities and milestones, which has already started. Expanding research aimed at preventing and treating the disease, accelerating efforts to identify early and pre-systematic stages of the disease. Coordinating research with international, public and private entities and facilitating translation of findings into medical practice and public health programs. We can't afford to do good research and treat it on a shelf. This problem is here today. We need to conduct research and translate it as quickly as possible.

Moderator: What about the second goal?

Dave Hoffman: Our second goal acknowledges in order to address this issue, we need a capable workforce. One that understands the complexities of dementia. This is going to take a significant amount of pre-service training for professionals and paraprofessionals as they prepare to begin careers and also in-service training for people who are in the field today so they understand the guidelines of best practices that are available.

Moderator: So schools of medicine, social work, nursing, certainly schools of public health are beginning to take this on as a priority and begin shaping the goal?

Dave Hoffman: We hope so.

Moderator: Have you explored the effectiveness of new models Dave?

Dave Hoffman: This is a process that's just beginning. It's going to take some time. The second goal under enhancing care and quality leads us to a key here. Safe and effective transitions. This is an area we know can be improved. A Harvard University study that was published this week confirmed that transitions to the hospital itself can cause complications and via driver for admissions to nursing home. We need to do what we can to keep people out of hospitals by providing better care. Coordinating care and support systems is an area where we need to make improvements and recognize that the presence of support has a direct impact both on the person with the disease and their caregiver. There are some groups that are impacted by dementia more than others. We need to address them from what about.

Moderator: What about the third goal?

Dave Hoffman: Expanding support to people with this condition and their families is going to take a full-court press. We need to ensure receipt of culturally-sensitive education and training of support materials. We need to enable family caregivers to continue to provide care, assist families where we can – more importantly, maintain dignity, safety and rights for the people with this condition, assess and address their housing needs. We know that the supports can make a difference. Dr. Mary Middleman at NYU has been studying this issue now for some 20 years. She has shown with long-term studies that with appropriate support, people with dementia can live with the community with dignity and safety and with caregivers feeling supported for up to a year and a half longer than otherwise expected.
Moderator: I once heard someone say, when we know better, we do better.

Dave Hoffman: Exactly.

Moderator: And the fourth goal, can you take us through that?

Dave Hoffman: Public awareness and engagement is going to be the key for our progress here. There are lots of myths and fears about dementia that need to be addressed. People need good information. This is a daunting issue and we don’t have a lot of resources to make this happen. It’s really important that we understand the facts about dementia.

Moderator: Finally tell us about the fifth goal Dave?

Dave Hoffman: The fifth goal is the accountability goal. It’s a plan built into monitoring the progress so that the public and constituent groups like the Alzheimer’s Association, state governments, healthcare providers and others, can hold one another accountable for progress on these goals. More importantly, the plan also links to other federal plans. It acknowledges right up front that dementia is not happening in a vacuum. One of the plans link to it to dementia. So that linkage is really important.

Moderator: Very important, it’s exciting to see the collaboration that is such an intricate part of the goal. What are the recommendations of the National Council?

Dave Hoffman: The National Council representing those non-federal members of the council also published a set of recommendations. Those recommendations tend to be more specific and more robust than the recommendations that were in the federal plan. They really kind of set the stage for the next version of the federal plan but they include things like increasing initiative, spanning basic translation and clinical research to address disparities. The council recommendations go far beyond some of the recommendations in the national plan. This is a process that's ongoing. So these recommendations are really going to help us move the plan forward as the month’s progress.

Moderator: Now, let me ask you this Dave. Will the aspect of the National Council recommendations, will they key in so to speak, once the goals are fully resolved or fully engaged and then they kick in? Or will there be a transition that takes place?

Dave Hoffman: That's really a good question. It's more of an evolutionary process. The recommendations of the council members are going to enhance the national plan in the iterations of the plan as it's published. That's an ongoing process. Council members are now talking about the 2013 plan so that's already occurring.

Moderator: So, it sounds like there will be a seamless transition if you will.

Dave Hoffman: We hope so.

Moderator: Okay. Were there recommendations regarding the funding?

Dave Hoffman: Yes. The council recommendations call for expanded funding and incentives for healthcare providers, for funding associate with state education and others to include key information about Alzheimer’s disease and all curricula for any profession or career track that affects long term services and support. Also
redesigning Medicaid reimbursement to encourage appropriate diagnosis of Alzheimer’s disease and to provide care planning to diagnose individuals and their caregivers. It's important that advanced care planning that we talked about earlier, is something that's reimbursed in the process not something just an added task for providers.

Moderator: Does the funding extend to all of the states?

Dave Hoffman: At this point, there's not enough funding for all states to engage in these activities. That's really a role for the public and the advocacy community to educate policy makers about that need.

Moderator: Very well, what are the other effects of the recommendation?

Dave Hoffman: Importantly, the recommendations called for a robust dementia capable system of long term services and support that will be available in every state. The state should ensure that paraprofessional caregivers are adequately trained and compensated. The process of diagnosis should include engaging the individual and family members in advanced care planning. Health and human services should ensure that health-related systems funded with federal resources should include chronic disease treatment and develop quality measures and indicators for the comprehensive care and treatment that we've been talking about.

Moderator: Dave, the plan for 2013 is under way. Is that correct?

Dave Hoffman: That is correct. The council meeting is scheduled for July and some of the subcommittee groups are in discussion.

Moderator: Good, Dave share with us the contributions made by New York State.

Dave Hoffman: New York State has a coordinating council on Alzheimer’s disease services and the committees of this group have deliberated over the past couple years and issued a report a few months. This was the second report from this council. There were significant contributions from the field both caregivers and providers and others. This report includes some ground-breaking recommendations. Dr. Shaw, our New York State Health Commissioners were interested in this report.

Moderator: What are New York State's recommendations?

Dave Hoffman: New York State recommends cognitive screening for everyone, age 65 and older as part of their normal healthcare. At their annual physical, if they need to make an emergency room visit or urgent care visit, the cognitive screening should be part of that care to include key information about dementia in all planning, to engage Alzheimer’s disease assistant centers, nine centers that are located around the state and other partners to develop this training, to explore possibilities and partnerships for public awareness and the providers should engage people dementia and their family advanced planning at the earliest opportunity. New York's report was actually out first.

Moderator: Wonderful! With New York State being so diverse and so large, the nine centers you speak of, are they far out as up in the north country and way out west and also in some of our urban markets, the urban and suburban and rural markets are being impacted at all by the nine centers?

Dave Hoffman: Absolutely, they are geographically dispersed from Long Island to Buffalo to Plattsburg to New York City. At the same time, we don't pretend we have enough Alzheimer’s disease centers.
Moderator: Well, this has been incredibly helpful information. I understand you have further resources to share with our viewers as well that they can access on the Internet?

Dave Hoffman: There's a slide with information for web links to the New York State Department of Health's web page. There's a dementia page that has number of links on it that people can use as well as information about dementia. There's a new federal site called Alzheimer’s.com that was just initiated last month. The National Alzheimer’s Project Act site is listed there. If people want to follow the activities of the National Council and all the meeting materials and background materials reside on that website. As I mentioned in the beginning, the Alzheimer’s Association site is a terrific resource for people and that's listed there as well.

Moderator: Dave, before we open this up for questions, I would like to give you an opportunity if you like, to give us your take-away points that you think are most valuable for our audience today.

Dave Hoffman: Thank you I think it's important for all of us to understand that the time to talk about dementia is now, that the problem is here and that the good news is policy makers are becoming aware of these issues. We're seeing things like the world health organization report in March and now national plan and this report from the New York State Advisory Council acknowledging the issue making some concrete recommendations and as you heard me say several times this morning, we all just need to work together.

Moderator: I agree. Thank you so much Dave. We will open it up for questions. We already have some questions that's have come in for you. The first question, you mentioned myths about Alzheimer’s, can you give us a couple examples?

Dave Hoffman: Sure. There is a myth associated with Alzheimer’s that it's caused by aluminum. Scientific study has closed no relationship between aluminum and Alzheimer’s. That's an important consideration because aluminum is found in many deodorants. I would encourage people to go to gone alz.org. There's a list of myths there.

Moderator: Thank you for that. Here's the next question, can medication slow on the set of Alzheimer’s disease?

Dave Hoffman: Currently there aren't any medications that slow on the set of the disease. There are medications on the market that can assist people with some of the symptoms associated with Alzheimer’s disease. I’m not a physician. I’m not going to give people advice about medication. I would encourage anyone who suspects a diagnosis of dementia or Alzheimer’s disease to talk to their healthcare provider and listen to their advice very carefully. Thank you. Here's a question that we hear quite frequently. Is Alzheimer’s disease de-genetic? That's a real good question. There was a long article in the New York Times about a family in Oklahoma where significant number of family members developed an early onset version of Alzheimer’s disease. We know that dementia is a set of diseases. It's not a single condition. Some of those diseases and some forms of Alzheimer’s disease have a genetic component. The research is ongoing. We don't know what that genetic component is. It's important that research continue.

Moderator: The funding will assist with the research.

Dave Hoffman: Absolutely.
Moderator: Here's a follow up question that corresponds nicely with that. It's just been e-mailed to us from Cincinnati. How much of Alzheimer’s funding or proposed funding is also or is associated with the Affordable Healthcare Act?

Dave Hoffman: Actually some of the numbers I mentioned, the $26 million that goes for things like workforce education and public education in the president’s proposed budgets are supposed to come from the prevention public health fund. A ground breaking fund that was part of the affordable care act, acknowledging right up front that our healthcare system today doesn’t do enough in prevention and that prevention is really going to be a key moving forward. As I mentioned before, congress hasn’t acted on those proposals yet.

Moderator: Thank you, here's a question that's coming from the New York Academy of Medicine. Any advancements that have been made regarding Alzheimer’s disease that you're aware of?

Dave Hoffman: Yes, I actually have been pleasantly surprised to see when I went back and tracked in the late press, on the Internet and on major newspapers like the New York Times and others. There had been published stories about Alzheimer’s research, every week this year. That’s a significant improvement over what we saw in the past. What it tells us is that dementia is in the news. It tends to be in the news when a new research study like that Harvard study about hospital transitions that I mentioned was published this week. I think it’s important for people to repass the headlines when they see those stories. That’s one way that the public and providers can be educated.

Moderator: That's an excellent point. Social media can also play a tremendous role in passing on those headlines and the valuable information that's out there. We touched upon some of this information early regarding diagnosis. How is Alzheimer’s disease diagnosed?

Dave Hoffman: As I said, I'm not a physician so I'm not an expert in diagnosis. It's not an easy diagnosis to make. When we look at that list of conditions that I mentioned, when two or more of those conditions are present, a healthcare provider can make a diagnosis of Alzheimer’s disease. It’s important for healthcare providers to consider that diagnosis, the old conventional wisdom was don’t tell the person they have dementia because there's not much we can do about it. The new conventional wisdom is, particularly after reading Mary Middleman's research, there's so much we can do in terms of helping the person with the condition and their caregivers prepare a plan, develop their care team, and get ready for the future that early information is better information.

Moderator: The earlier the better. Here's an e-mail question coming from Florida. Any information by new diagnostic tests using pet scans?

Dave Hoffman: This is not an area of my expertise. I’m aware there's research and test scans and diagnosis. I would encourage the questioner to go to National Institutes of Health web page where they can read about what research is currently happening.

Moderator: Thank you. You've done a tremendous job today underscoring, highlighting, emphasizing the tremendous burden often times taken on by caregivers. Here's this question, what advice do you give to caregivers?

Dave Hoffman: My advice to caregivers is to take advantage of any resources in their community that are available to help them. Reach out to friends and family. Reach out to community groups like the Alzheimer’s Association that have support group activities, that have caregiver hotlines where you can call an 800 number.
at 2:00 in the morning where mom and pop are wondering around the house and a trained individual can help you work through that situation and find a satisfactory conclusion. Once again, the website to find resources to the Alzheimer’s is alz.org or folks can find that information at the New York State Health page.

Moderator: Here’s a question coming from the phone. How do they determine the difference between Alzheimer’s disease and other dementia?

Dave Hoffman: The differences are designated primarily through a variety of tests that are done and the test are very important because there are some forms of dementia that some forms of conditions where the symptoms present as dementia where they are reversal. Sometimes dementia can be where they are taking too many medications. It’s important that the test be done to avoid that situation and correct the problem when it can be corrected. Some types of dementia can be diagnosed better on using imaging. I'm not an expert on this, but the testing that is done as part of the diagnostic process, typically rules out some of those conditions.

Moderator: Thank you, here's a great question that's came in via the phone. Can you address memory? Is there research that these memory cafes help patients and their caregivers?

Dave Hoffman: I can't address that. I'm not familiar with cafes. What I can say, there's a variety of activities happening that we read about all the time. Use of the arts, use of museums, use of music, choirs, etcetera for people with various forms of dementia that have been shown to have a calming effect and to enhance their life to give people a better quality of life.

Moderator: Thank you. I believe this is the last question that we have today for you. When will the next national plan be released?

Dave Hoffman: The next national plan is scheduled to be released in May of 2013. The first national plan came out in May of 2012. We're looking for that to be an annual process. Council members will push the federal government to meet that deadline.

Moderator: Dave, you have come here today armed with a tremendous amount of information. I want to thank you on behalf of Public Health Live for the great work that you’re doing in New York State through the Office of Health Insurance Programs and helping caregivers and those with Alzheimer’s and dementia.

Dave Hoffman: Thank you.

Moderator: Thank you very much for joining us today. Please remember to fill out your evaluations online, your feedback is always helpful to the development of our program and continuing education credit is available. Learners must visit www.phlive.org. You can also download the Companion Guide of this broadcast on our website phlive.org. The Companion Guide will provide you with learning activities to help further your knowledge and understanding. An archive of this web cast will be on our website within two weeks. Please join us on July 19th for the next Public Health Live broadcast on using social media in public health. I'm Joel Alexander, thanks so much for joining us on Public Health Live. Thank you.

Dave Hoffman: Thanks Joel.