

**NWX-HHS-AOA-1**

**Moderator: Amy Wiatr-Rodriguez  
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12:30 pm CT**

Coordinator: Good afternoon and thank you for standing by. All participants will be able to listen only until the question-and-answer portion of the call. At that time to ask a question, please press star 1. This conference is being recorded. If you have any objections, you may disconnect at this time.

I would now like to turn the call over to Amy Wiatr-Rodriguez. You may begin.

Amy Wiatr-Rodriguez: Great. Thank you so much. Welcome everyone. I am Amy Wiatr-Rodriguez with the Administration on Aging within the Administration for Community Living, and I'll be moderating today's webinar Younger Onset Dementia -- which is the fourth in a 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 e-mail 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 e-mailed you, you can also go to [www-dot-webex -- W-E-B-E-X -- dot-com](http://www-dot-webex--W-E-B-E-X--dot-com), click on the Attend a Meeting button at the top of the page and then enter the meeting number -- which is 664390009.

If you have any problems with getting into WebEx, please call WebEx technical support at 866-569-3239. Occasionally, there are, you know, Web browser settings or other things that I don't know how to talk you through, but the WebEx technical support folks hopefully can.

Secondly, as our operator mentioned, all participants are in listen-only mode. However, we welcome your questions throughout the course of this webinar. There are two ways you can ask your questions, and first is through that Web chat feature in WebEx. You can enter your questions; we'll sort through them and answer them as best as we can when we take breaks for questions after each presenter.

And then in addition after the presenters wrap up, we will offer you a chance to ask your questions through the audio line. When that time comes, the operator will give you instructions how to queue up to ask your questions.

If there are any questions we can't answer during the course of this webinar, we'll follow up with you to answer them. If you think of any questions after the webinar, you can also e-mail them to us at my e-mail address -- which is [A-M-Y-dot-W-I-A-T-R--@-ACL-dot-HHS-dot-gov](mailto:A-M-Y-dot-W-I-A-T-R--@-ACL-dot-HHS-dot-gov) -- or to any of the e-mail addresses that are included in the PowerPoint slides that are the basis for this webinar.

And as the operator mentioned, we are recording this webinar. We will post the recording, the slides and a transcript on our AOA Web site at [www-dot-AOA-dot-gov](http://www-dot-AOA-dot-gov) as soon as possible.

So now getting to the fun stuff, our speakers today include Creighton Phelps, Ph.D., Director of the Alzheimer's Disease Centers Program with the National Institute on Aging; Darby Morhardt, MSW, LCSW, Research Associate Professor and Director of Education with the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University; Sandra Weintraub, Ph.D. with the Cognitive Neurology and Alzheimer's Disease Center, Northwestern University; and Sharon Denny, Program Director with the Association for Frontotemporal Degeneration.

At this point I'd like to turn it over to Creighton Phelps with the Alzheimer's Disease Centers Program at NIA to kickoff our webinar. Creighton?

Creighton Phelps: Thank you, Amy. On behalf of the National Institute on Aging, I would like to welcome everybody to this important webinar -- which will include expert presentations on the nature and importance of the Younger Onset Dementias.

Dementia, as most of you know, is an impairment of cognitive function which gets progressively worse over time and has an impact on daily life. Most people when they think of dementia think of Alzheimer's disease -- which is the most common type of dementia. However, the majority of Alzheimer's cases occur in later life after the age of 65.

When dementia occurs before age 65, it is termed Younger Onset Dementia and may be caused by Alzheimer's but also there are other causes for Younger Onset Dementia -- including some which are treatable, such as normal pressure hydrocephalus, infections and tumors. Dominantly inherited Alzheimer's disease, a rare genetic variety of the disease, and other less understood risk factors genes for Alzheimer's run in some families where Younger Onset Disease occurs.

Another major cause of Younger Onset Dementia is a family of diseases called the Frontotemporal Disorders or FTD -- which will be featured in today's presentation from experts at Northwestern University Medical Center in Chicago -- which is one of the world's best places for the evaluation of these diseases -- and also from the Association for Frontotemporal Dementia, an organization that provides information and support to patients and caregivers dealing with FTD.

Because detection and diagnosis of Younger Onset Dementia is complex and is often confused with psychiatric disorders, it's important to have patients evaluated in specialty clinics with experience in dealing with the various causes.

The NIA sponsors a network of Alzheimer's centers - could you add the next slide, please -- which are also prepared to diagnose the different causes of the Younger Onset Dementias and provide expert guidance to patients and families. You can see on the map that there are 27 main centers and two satellite centers where patients can be referred from communities that may not have access to specialty clinics locally.

I look forward to hearing from the experts on this webinar, and we are very privileged to have them with us. And with that I'll turn it back over to Amy.

Amy Wiatr-Rodriguez: Great. Thank you so much, Creighton. And next we're going to hear from Darby Morhardt with the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University, and she's going to give us an overview of the scale and scope of issues related to Younger Onset Dementia. So, Darby?

Darby Morhardt: Great. Thank you, Amy. I'm delighted to be a part of this webinar on Younger Onset Dementia and to have the opportunity to speak to so many people across the nation about this topic.

Just to give an outline, I will be defining and describing Younger Onset Dementia and setting the stage for Dr. Weintraub, who will be going into more depth regarding the different dementias. I will then be discussing the impact of Younger Onset Dementia on the diagnosed person and family and the challenges they face. And I will close with a discussion of some of the available resources.

Next slide.

And as we just heard from Dr. Phelps, what is dementia: and dementia is an umbrella term that describes symptoms. It's not a specific diagnosis and can be defined as a condition of the mind caused by a disease of the brain. And the way you would identify a dementia is by acknowledging a decline from a prior level of functioning and cognition, emotion and/or behavior. And in terms of the course, a dementia by definition progressively worsens over time. There are many causes of dementia.

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The common perception that dementia is a condition of older age belies the fact that people under 65 years and younger do present with dementia. And a definition of Younger Onset Dementia is basically that the symptoms are first occurring in a person under the age of 65.

Dementia is devastating at any age, but a diagnosis in younger patients presents particular challenges. The differential diagnosis is much broader

when a person under the age of 60 or 65 presents with cognitive decline and there is a higher prevalence that it can be a non-Alzheimer dementia. It is a greater probability that the disease is genetically inherited. And if it is Alzheimer's disease as the underlying diagnosis, it often presents differently. And I will explain that further in my upcoming slides, as will Dr. Weintraub in her presentation.

Next slide.

Persons with Younger Onset Dementia are also likely to be healthier and less likely to have coexisting illnesses, such as vascular disease, diabetes or hearing loss or other sensory changes. Younger Onset Dementia is also sometimes confused with early stage dementia. So again Young Onset Dementia is when the illness strikes individuals under 65 years of age compared to early stage dementia -- which refers to the stage of the illness, so that symptoms are in the mild stage in a person of any age.

Next slide.

In 2006, the Alzheimer's Association published this report on the prevalence of Younger Onset Dementia. And it's stating that approximately 220,000 individuals are living with Younger Onset Dementia.

The Frontotemporal Degeneration disorders -- which are most commonly found in Younger Onset Dementia -- are estimated to affect 50 to 60,000 people in the United States.

However both of these numbers are really very incomplete. It's an incomplete picture, as really more data is needed to understand the prevalence of these disorders.

Next slide.

So this is a slide that shows the differential diagnosis of Younger Onset Dementia, and as I said before, really shows how much broader the diagnosis is than that of a Later Onset Dementia.

This slide shows that Alzheimer's disease while it certainly presents with the initial symptoms of memory loss can often present as the syndrome of Posterior Cortical Atrophy or Primary Progressive Aphasia in younger individuals.

There's also a class of disorders called Frontotemporal Degeneration -- which can also present as the clinical syndromes of Primary Progressive Aphasia, behavioral variant Frontotemporal Degeneration or bvFTD, Progressive Supranuclear Palsy, Corticobasal Degeneration and FTD-MND or FTD-Motor Neuron Disease. And I'm going to describe these briefly.

Next slide.

So to start off, Alzheimer's disease. The more typical presentation of Alzheimer's as we know is a progressive illness that begins in the area of the brain responsible for memory. So the major symptom is the inability to learn and retain new information, to forget current and personal events, conversations, to repeat questions and stories, to misplace things, to have some spatial disorientation and typically, as Dr. Phelps stated, the age of onset is over the age of 65 with aging being the biggest risk factor for Alzheimer's disease.

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But another form of Alzheimer's disease is Posterior Cortical Atrophy or Benson's syndrome and some call it the visual variant of Alzheimer's disease. And people with this disorder have as their first symptoms a decline in visual processing skills but they retain an intact memory and language abilities in the early stages. So instead of the disease affecting the memory center of the brain, the disease affects the visual part of the brain. And it's estimated that 5 to 15% of people with Alzheimer's disease have PCA.

Next slide, please.

So Frontotemporal Degeneration is a Younger Onset Dementia and it presents in primarily three types -- the language type, the behavioral type and the motor type -- and let's talk about the language type first.

Next slide, please.

So language type or more typically called Primary Progressive Aphasia is a clinical syndrome that's diagnosed when the following are present, so when aphasia is present or there's a disorder of spoken or written language, where that aphasia then is progressive and is caused by a degenerative brain disease and where that aphasia is the most salient feature and the chief cause of their daily living limitations. So that means that it's primary and it's typically the only symptom for the first two years.

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And the behavioral type or behavioral variant of Frontotemporal Degeneration is where there's a progressive deterioration of behavior or cognition. So people will see behavioral disinhibition, saying and doing things they never

would have dreamed of doing or saying before. Also there can be signs of early apathy or disinterest; also emotions are affected in frontotemporal degeneration of the behavioral variant where they lack sympathy or ability to be empathic toward others. Often there are symptoms of perseveration and compulsive ritualistic behavior, hyperorality and dietary changes are also common. And also in the behavioral variant FTD the memory and visuo-spatial symptoms are spared.

Next slide, please.

And then in the motor type the Progressive Supranuclear Palsy these include, the symptoms include balance, vision, speech and swallowing problems, a worsened memory and mood, body stiffness, personality changes. And what is often most salient is that they are unable to look down voluntarily, so there's that vision change.

In CBD or Cortical Basal Degeneration it's very similar to PSP and it's often difficult to differentiate because they also have balance, vision, speech and swallowing problems and stiffness, slowness and clumsiness and memory or behavior problems.

And then lastly the FTD-MND is a combination of FTD and ALS -- which causes changes in behavior and/or language with muscle weakness, shrinking and jerking.

And so this is it basically. I've gone through this very broadly. But I wanted to just set the stage for an understanding of the great variability in Younger Onset Dementia and Dr. Weintraub's presentation will go into much more detail about these disorders.

Next slide, please.

So now I'd like to shift to the impact these disorders that occur at a younger age of onset have on the person and their family.

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One of the difficulties for younger people developing dementia is obtaining a definite diagnosis. Initial symptoms are commonly misdiagnosed as psychiatric disorders resulting in a delay of several years between the onset of presenting symptoms and a correct diagnosis, and this can cause much stress for the person and their family.

The onset of speech difficulties, loss of memory or the changes in personality and behavior in younger persons are often thought to be the result of anxiety or depression or bipolar disorder or midlife stress. And particularly in someone who's younger, most physicians do not expect the person to be suffering a neurodegenerative disease and many individuals will experience several evaluations and numerous tests before an accurate diagnosis is reached.

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Perhaps more than at any other time across the life course the diagnosis of dementia in younger people is likely to have a complex range of affects on all family members. Basically this is a different developmental stage of life for this family, and the impact is different when there are dependent children or young adults living in the home who are often trusted into caregiving for their parent and also being of support to the well parent.

Some teenagers and young adults are naturally trying to leave home and this decision around whether they do or not will likely be affected by their parents or how they leave home will be affected by their parent's illness.

There are also situations where an older parent who may have their own frailties is caring for a middle-age child with Younger Onset Dementia.

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The psychological and social, family and financial issues that affect the individuals with Young Onset Dementia are very different than those that affect individuals with Late Onset Dementia. Again not only the patient is younger, the entire family is younger.

So it's difficult to perform job tasks when it is difficult to carry on conversations or if one has behavioral problems or has increasing forgetfulness. There are often misunderstandings by employers and coworkers. Individuals are at risk for receiving poor performance evaluations, bringing a loss of self-esteem and a feeling of diminished productivity, and they may be terminated from their positions before the illness is completely understood.

So therefore the person with Younger Onset Dementia has to stop working at a time when they're probably in the prime of their working career, and they are still saving for retirement and supporting their younger family. And because of this loss of employment, the well spouse may need to seek additional work to meet the family's financial needs.

The loss of income also impacts the affordability of future long-term care. Many have just not saved enough yet and may also have young children that they are supporting.

Next slide, please.

And this is a couple of quotes from some family members regarding just that issue of the loss of employment and job-related income and dreams for their future.

Next slide, please.

Historically persons with Younger Onset Dementia of any kind have had a very grueling and lengthy Social Security Disability Insurance application process, usually with multiple denials and appeals. However, in 2009 the Social Security Administration rolled out its Compassionate Allowances Program in an effort to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards.

So due to the successful advocacy efforts by the Association for Frontotemporal Degeneration in March of 2009, FTD was one of the first 50 conditions named in the Social Security Administration's Compassionate Allowances list. And then Alzheimer's disease and Primary Progressive Aphasia were two of the 38 conditions subsequently added in 2010. And this was a major advancement toward helping persons with Younger Onset Dementia quickly get on track for Medicare.

However after approval of Social Security Disability Insurance a patient must still wait two years before they are eligible for Medicare benefits. And

unfortunately during this waiting period some individuals can go bankrupt and nearly a quarter of those caught in the two-year waiting period between SSDI and Medicare can go the entire two years without insurance.

Next slide, please.

In a 2011 literature review by Svanberg and others, they found that caregivers of Younger Onset persons with dementia have significantly higher levels of burden and that caregivers of persons with FTD have higher burden compared to Alzheimer's disease and that behavioral symptoms of disinhibition and apathy were experienced more frequently and intensely.

The next slide, please.

There's a general lack of understanding of Younger Onset Dementia among health care providers and social service agencies who are far more familiar with Alzheimer's disease in the older demographic. And as a result it's difficult to find appropriate home and community based services willing and able to accept persons with Younger Onset Dementia.

For those who can afford to hire a private companion, a barrier is finding professional caregivers with training or experience in the care of persons who are younger and who have a non-Alzheimer dementia.

Next slide, please.

And this is a couple of quotes of individuals who had a lot of difficulty finding an adult daycare facility or respite care for a physically active younger person. And I've run into this many times where nursing homes have a lot of

difficulty considering younger patients with especially frontotemporal dementia.

Next slide, please.

So I'd like to spend the next few slides just discussing the impact of Younger Onset Dementia on different members of the family. And I want to point out that insight is relatively well preserved in persons with particularly Primary Progressive Aphasia and also in some people with Alzheimer's disease in the very earliest stages.

And there has been one particular study done that found that 34% of PPA patients were clinically depressed and even in the clinically non-depressed subjects they reported more symptoms of depression than the control subjects.

Also the number of depressive symptoms is associated with a decline in the ability to name things. Persons with memory loss and visuo-spatial difficulties can also experience depression in response to the diagnosis and also to the ways that they feel stigmatized and marginalized by the illness.

In the Younger Onset and Early Stage support groups around the country, a common theme from diagnosed individuals is, "I'm still here and stop treating me like I'm not."

However, persons with behavioral variant FTD and Alzheimer's disease and other non-Alzheimer's dementias, if they progress, the part of the brain that regulates insight can be affected. And these personally and behavior changes can be very disruptive to families.

With and without these additional changes as Young Onset Dementia progresses, it creates increasing dependency on others who must begin to take over tasks that the person with Young Onset Dementia is no longer capable of managing. And families find that they are increasingly in that role of caregiver.

Next slide, please.

It's also important to understand the impact that children face with a parent who has Younger Onset Dementia. No matter the age, they're losing a parent at a key developmental time of their life, and they're grieving the loss of that parent.

They may feel responsible for causing the illness. They may feel they may catch it. They may assume caregiving roles, like assisting with caregiver tasks and providing support to the well parent. And it's also important to recognize the positive and that children indeed can be incredibly resilient.

It's a very defining experience for the child and the entire family -- which can have negative and positive ramifications and care must be taken to understand how everyone is coping. Each person in the family is experiencing this in their own way.

Next slide, please.

And the impact of the illness on the partner or spouse is in the loss of companionship, someone with whom they once made crucial decisions and had conversations at the end of the day. The person is in the dual-caregiving role for their spouse, their young children -- which complicates balancing the care with maintaining a life of their own. And as I've said, roles in the family

are shifting, reciprocity in the relationship diminishes and they can become more like a parent.

There is a loss of intimacy and sexuality, and partners and spouses talk about feelings of grief and stress, guilt, depression and anxiety. But again the emotional impact is different for each person.

The next slide.

And this is a couple of quotes from partner spouses of persons with Young Onset Dementia.

Next slide, please.

So what is available for families? Next slide, please.

It's recommended that all persons diagnosed with Younger Onset Dementia, as with a dementia of any age, establish a power of attorney for health care and finances. Long-term care insurance must be obtained prior to the diagnosis, and we've already discussed SSDI and the Medicare two-year wait. Individuals also need to recognize the availability of disability services for those under the age of 59 and aging services for those over the age of 60, and I will discuss these further.

The next slide, please.

No matter what areas of the brain are first affected, the disease progresses to affect other brain areas and create new symptoms and changes in abilities of the person with the illness. So the family is in the position of adjusting to these changes over the course of the illness. So this slide and the next have

examples of services for persons with Younger Onset Dementia and their families.

Finding a social worker or psychologist knowledgeable regarding the Younger Onset Dementias may be very helpful in navigating families through the very difficult health and social service system. And counseling can take the form of individual counseling for the person with the illness, their family or support groups. And due to the nature of the losses, the creative arts can also be very helpful options.

Next slide, please.

Long-term care services can include in-home care companions, adult day services and respite programs for those who are trying to maintain living in their own homes. More intense supports, such as assisted living and nursing home care, may be used as the disease progresses.

As the disease reaches the more advanced stages, it is important to help families understand the benefits of palliative care and hospice. And as we'll discuss in the next slide, the funding sources for these different types of services and supports may vary -- which is another reason why proper and prompt diagnosis is important to allow people with Younger Onset Dementia and their families to plan accordingly.

Next slide.

Long-term care services can be accessed and financed through private payment or private long-term care insurance as well as through various publicly funded aging and disability programs.

The types of services, eligibility requirements and what funding is available for them can vary widely from program to program and location to location. For example some people with Younger Onset Dementia might be able to access Medicaid waiver programs depending on what state they live in. It's important to recognize in this webinar that when the Older Americans Act was reauthorized in 2006, the National Family Caregiver Support Program was expanded to allow for service to caregivers of persons with Alzheimer's or related disorders of any age.

However, types and available amounts of Older Americans Act services may vary, and there are other state and local sources that may be available, too. So contacting your local area agency on aging or Aging and Disability Resource Center is recommended to find out what's available. And the elder care locator link, [eldercare.gov](http://eldercare.gov), will give you that local contact information for anywhere in the country.

Next slide, please.

And this is just a list of organizations that are for Younger Onset Dementias -- the Association for Frontotemporal Degeneration, CurePSP, the NAA, Alzheimer's Association and ADEAR through the National Institute on Aging.

Next slide.

And then there have been an increasing number of non-Alzheimer's caregiver conferences throughout the country -- particularly those caring for someone with FTD -- and I wanted to take this opportunity to make everyone aware of our annual Caregiver Conference in Chicago for persons with FTD and PPA to be held on November 4. And you're very welcome to attend.

Our director, Marsel Mesulam, will give the keynote address this year on the state of research and treatment in FTD and PPA. A speech language pathologist will discuss interventions for language changes and a social worker will discuss coping with relationship and behavior changes. And then we have assorted breakout sessions in the afternoon.

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And last year's conference booklet can be downloaded on our Web site free of charge. Feel free to take a look at that.

Next slide.

And then the benefit of a webinar like this is that we are able to raise awareness of Younger Onset Dementia and particularly the variability in the presentation and diagnosis of Younger Onset Dementia. And here are some quotes from families who have been very frustrated by the lack of awareness of Younger Onset Dementia as they've tried to navigate through various systems.

And next slide, please.

And in conclusion the differential diagnosis of Younger Onset Dementia as we said is much broader. Many may have a non-Alzheimer dementia. Early diagnosis and information lead to earlier treatment and planning. And persons with Younger Onset Dementia in their families have different needs for services and support.

Next slide.

And I just wanted to show you some images of persons with - the persons who created these have either a Primary Progressive Aphasia or Frontotemporal Degeneration behavioral variant.

And next slide.

And I just wanted to acknowledge my colleagues at Northwestern and our center for all this information. And with that I will end my part.

Amy Wiatr-Rodriguez: Great. Thank you so much, Darby. This is Amy. And I know we have a number of questions coming in through the chat feature. I don't know that we'll be able to answer them all right now, since we have other presenters coming up, but maybe we'll just do one of them.

And one came in from Debra. She was asking, "If a person is terminated from a job where he or she was covered by disability insurance and later gets a diagnosis of Younger Onset Dementia, is there any way that person can go back and get benefits through the former employer or are there any attorney referrals that might be made in a situation like this?"

Darby Morhardt: Yes. And this is something that I would absolutely refer to an elder care lawyer immediately, and they should be able to help navigate through that situation.

Amy Wiatr-Rodriguez: Okay. And maybe I'll see if I can get one other question that had come in. A question came from Kathy and I think she just wanted to kind of comment or confirm that if a person has been diagnosed with an Early Onset Dementia doubts that they would be accepted for private long-term care insurance. So in other words, for people to benefit from private long-term care

insurance, they would already need to have a policy in place before the onset, correct?

Darby Morhardt: Yes correct. Right. Once you get a diagnosis, it's too late.

Amy Wiatr-Rodriguez: Okay. Wonderful. And well like I said we've got other questions coming in. We'll try to perhaps we'll get a chance to answer those later in the webinar or if not, we definitely will answer them one way or another. But again I want to thank you, Darby, and now I want to go next to hear from Dr. Sandra Weintraub, who's also with the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University. And she is going to be discussing the detection, diagnosis and research needs for those with Younger Onset Dementias. So Dr. Weintraub?

Dr. Sandra Weintraub: Thank you very much, Amy, and I'm really delighted to be participating in this conference. Next slide, please.

Just very briefly these are my disclosures. I don't have very much to disclose, but whatever it is, is right here.

I just want to say that some of the things that I'll be covering in the next few minutes will overlap with what Darby Morhardt has told you, but coming at it from a slightly different direction of kind of trying to understand more of the biology that underlies these disorders.

Next slide, please.

So just to make sure we're on the same page with definitions. Dementia is a clinical syndrome. That means that it's what the person is experiencing and what the doctor examines. And it is a gradual onset and progressive decline in

abilities and/or behavior and it can also affect motor function. So I think we all think of dementia as being memory loss, but it really goes beyond that. Anything that your brain does is grist for the mill for a dementia process.

Dementia is differentiated from normal aging changes because it interferes with daily activities and the cognitive decline is so great or the behavioral decline that there is a need for assistance and supervision.

These dementias also tend to foreshorten life. You are not going to live as long with a diagnosis of a degenerative dementia as you will if you don't have one. And the most common cause of these dementia syndromes in both young and older people is neurodegenerative disease, much more so in older people, a little less so in younger people.

Next, please.

Again the Older Onset Dementia is the most common form and the onset of symptoms is 65 years or older. The Younger Onset is symptoms occurring under the age of 65. And unfortunately there are dementias in individuals as young as their 20s, but that's very, very rare. Most commonly when we talk about Younger Onset, we're talking about people in their late 40s and 50s.

Next.

So we have this dementia. We've described it. What causes it? What causes Younger Onset Dementia? And I've broken these down into two major classes. One is a class of diseases that are potentially treatable and the other is a class of diseases that are currently incurable.

In the treatable diseases, we can have vascular issues, like stroke. We can have toxic and metabolic disorders, like too many medications to the wrong medications or metabolic diseases like diabetes or kidney failure. Infections can give rise to what looks like a dementia. Undiagnosed epilepsy and brain tumors, especially in younger persons who have the dementia syndrome, we worry a lot about a brain tumor and that's something we want to rule out.

Under the incurable diseases the class of incurable diseases falls under the rubric neurodegenerative and that means that these are diseases that destroy brain cells that cause a degeneration of neurons. There are two major classes of those diseases. One is Alzheimer's disease neuropathology and the other is the non-Alzheimer neuropathologies, and I'm going to show you pictures of these so that they're clearer in your mind.

Under the non-Alzheimer neuropathologies we have Diffuse Lewy Body disease, the Frontotemporal Degenerations and Prion diseases.

Next.

The Frontotemporal Degenerations, as Darby already told you, cause three kinds of a dementia syndrome. There is a behavior or personality decline, also known as bvFTD, the language decline that is known as Primary Progressive Aphasia and the motor symptoms and movement disorders decline. And here in this case we're talking about movement disorders that also have a dementia component because you can have a movement disorder like Parkinson's where there's no dementia at all. So this subtype of the movement disorder is a movement disorder plus changes in cognition and behavior.

And these diseases are all caused by the three culprits at the bottom of the slide. These are microscopic pictures under the microscope taken from the

brains of individuals who during their lifetime had one of these syndromes. And what we can see here is these Frontotemporal Degenerations have different protein abnormalities. The one on the left is called TDP-43, the one in the middle is called FUS and the one on the right is called Tauopathy-Pick's disease.

And you can see that under the microscope there is absolutely no mistaking one from the next. But it is in the living patient that we really cannot tell what's in their brain. We can make a guess, but we don't really know for sure.

Next slide.

Now we also have Alzheimer neuropathology -- which is shown in this figure on the bottom of the slide. And again you can see that looks very different from the FTD neuropathologies I showed you on the earlier slide. So under the microscope this is what Alzheimer's looks like. And it has two abnormal proteins called tau and amyloid.

However, in the dementias that this disorder causes we have some overlap with the dementias caused by the FTDs. We have a language decline -- which is the most frequent overlap category of Primary Progressive Aphasia. But more typically the Alzheimer's neuropathology causes memory loss -- which is also known now as dementia due to AD neuropathology. And in these individuals the biggest problem initially is short-term memory loss.

And then there's also, as Darby told you, the visuo-spatial dysfunction -- which is called Posterior Cortical Atrophy. So the three pink boxes at the top is what the individual experiences in the form of symptoms and the figure at the bottom is what's causing these abnormalities.

Next slide, please.

The diagnosis of the language dementia is made on the basis of the following. The earliest symptoms include word searching during speech. A patient may say the wrong words or may make errors in producing words.

Some individuals may not have that much difficulty speaking, but they don't really understand what you're saying. So one patient came in to see me and the wife said he asked - I asked for him to pass the salt and he said, "Salt? What is salt?" so even a simple word.

Spelling and writing errors, grammatical omissions or errors. In these individuals the reason they get this particular diagnostic label is that they don't have short-term memory deficits. They can't think of words, but that's very different from the other kinds of memory problems we've heard about, like misplacing and forgetting.

Next slide.

The diagnosis of bvFTD -- which is a personality behavior dementia -- consists of having one or more of the following. A loss of sympathy or empathy, changes in one's usual way of behaving. Some people have never behaved well. What we're looking for is a change; okay so just because somebody has gruff behavior or is disinhibited doesn't mean they have FTD. But if they were once kind and considerate and polite and become slowly a different character, then we worry about bvFTD.

There's inappropriate judgment, loss of initiative. Some individuals can have mood disorders but they don't really have a true depression. Depression really requires a lot of cognitive ability, believe it or not, and in bvFTD what might

be misinterpreted as depression is really apathy or just a total lack of initiative of motivation.

Next please. Excuse me.

In the dementia due to Alzheimer neuropathology, as I said earlier, the symptoms are more of a short-term memory loss. So these individuals don't have personality changes, they don't have visuo-spatial changes, they don't have language changes but they can't remember what happened maybe even as little as five minutes ago or an hour ago.

Other symptoms of forgetting are getting lost in a familiar neighborhood. And occasionally however, as I also said earlier, we can have atypical symptoms that are associated with Alzheimer neuropathologies, such as PPA or the visuo-spatial abnormalities. But these clinical syndromes are not as common with Alzheimer neuropathology as is the memory loss.

Next slide.

The movement disorders, the symptoms associated with movement disorders are tremor and rigidity -- which are Parkinson-like. Individuals with ALS or Lou Gehrig's disease have fasciculations or twitches or little ripples under the skin that are very characteristic. Individuals with movement disorders often have difficulty walking. They may fall a lot. They may feel unsteady on their feet.

The eye movement abnormalities that Darby Morhardt mentioned to you are very characteristic of Progressive Supranuclear Palsy. And in the examination the doctor asks the patient to look way up at the ceiling without moving their head at all and most of us can do that. But individuals with this disorder have

a frozen gaze. They can't look way up or way down. And of course these movement disorders are accompanied by dementia symptoms.

Next, please.

Darby has already gone over this with you, so I will not repeat it. Next, please.

As I told you earlier, when we go under the microscope, we can't be mistaken. We can't mistake Pick's disease -- which is in the upper right-hand figure -- with Alzheimer's -- which is in the lower left-hand figure. Those diagnoses are 100% under the microscope. They're not confusable with one another.

And just to show you the comparison of what these diseases look like under the microscope compared with a normal brain, normal brain tissue is in the middle figure in the bottom row. So we don't see any of those nasty neurofibrillary tangles or amyloid plaques or cortical Lewy bodies or tau inclusions or anything else that characterize the neurodegenerative diseases that cause Younger Onset Dementia.

Next, please.

So why do some people have memory loss and others have language loss and others have changes in personality if the underlying neuropathology at postmortem brain autopsy could be the same? You can have Alzheimer neuropathology, you can have language dementia or you can have memory dementia.

And the answer to that question is that the symptoms that the individual patient experiences depend on which part of the brain the disease decides to attack. And this is an area which is a huge void in terms of how much we

understand about how the diseases decide which system in the brain they're going to attack.

Next, please.

This shows a PET scan and what you're looking at here is a brain. You're looking from the top of the head and we're seeing the left side of the brain on the left and the right on the right. And if we were to put the eyes in here, they would be way at the top of the figures in the front.

And what you're seeing is that this brain is not showing normal metabolism indicated by the dark regions primarily on the left side. This is a patient with a Primary Progressive Aphasia and language is controlled by the left side of our brains.

And so what we can see here is in the early stages of this patient's illness there was a decreased metabolism in the language areas and all the other light areas are functioning normally. And these are scans of two different patients -- one was very, very early on the left and one was a little bit more advanced in their disease on the right.

Next slide, please.

Contrast that with the scan taken from somebody with behavioral variant Frontotemporal Dementia where their ability to show normal metabolism is reduced in the frontal lobes bilaterally, and this is why these diseases are called Frontal Degenerations. And you can see that the frontal lobes in individuals normally control your behavior and they control your social interpersonal skills and your judgment. So where in the brain the disease settles determines the kinds of symptoms an individual is going to have.

Next, please.

So here are some facts. In Older Onset Dementia, the most common cause is Alzheimer's neurodegenerative disease. Younger Onset can be caused by many other diseases -- including the Frontotemporal Degeneration, stroke, brain tumor, traumatic brain injury, autoimmune disorders and Alzheimer neuropathology.

So it's important to work up any person with a dementia but especially a younger individual because the chances that you may find something treatable are higher than in older individuals.

Next, please.

Two to five percent of Young Onset Alzheimer's is caused by genetic mutations that run in families, so it's kind of like Huntington's. If you get a gene, you're going to get the disease. But it's only 2 to 5% of individuals with Alzheimer's disease that is caused by genetic mutations.

In bvFTD it's a little bit different because the number of cases due to genetic inheritance is much higher. It's about 10 to 20% and that raises a whole other bunch of issues for families coping with these disorders because it may be something that's being passed on to their children.

Next.

We have had a tremendous explosion of information in the frontotemporal degeneration field. We now have six known genetic mutations that cause Young Onset Frontotemporal Degeneration. And I don't intend to go through

each one of these here, but I have put them down on this slide for your future reference if you're interested in the different chromosomes and the different protein abnormalities that these mutations are associated with.

Next.

In Young Onset Alzheimer's disease there are three known genetic mutations -- Presenilin 1, Presenilin 2 and the Amyloid Precursor Protein genes. So there are much fewer genetic mutations associated with Alzheimer neuropathology than with FTD.

Next slide.

If there's one thing that I really want to emphasize in this webinar is that it's really important if at all possible to get state-of-the-art evaluation because it avoids misdiagnosis and lost time. We are very fortunate to be in a specialty center for these unusual Younger Onset Dementias, and so we have the tools, we have the know-how.

But we also have seen many train wrecks of people having been from one doctor to another, losing their job, maybe getting divorced, alienating themselves from their children and finally come to find out that they have a, quote, unquote, real disease as opposed to something that they're just changing their personality or they don't like their spouse anymore.

Neuropsychological assessment provides objective evidence of the cognitive and behavioral deficits -- is this normal or it's not normal. A behavioral neurology evaluation is done by a neurologist who specializes in dementia. Unusual motor symptoms, is there another possibly curable medical cause. The neurologist would be able to investigate those questions.

Psychiatric evaluation can also be very helpful because the symptoms sometimes can be confused with psychiatric disease. And so the psychiatric evaluation can help you determine if you're dealing with something that's potentially treatable. But another important role is that patients with the FTDs often have lots of behavioral issues and may need medication just to help control their symptoms.

Laboratory tests include an MRI -- which looks at the structure of the brain -- a PET scan -- which looks at the function of the brain. You can also do cerebrospinal fluid tests to look for evidence of Alzheimer pathology. And we do a series of blood tests, not because they tell us about the different neurodegenerative dementias but because they help us uncover things like thyroid disorder or diabetes that could be causing the dementia.

And so the idea for the laboratory tests is to detect the known features of neurodegenerative diseases and to rule out all the other causes.

Next slide.

The social work evaluation we consider to be just about as important if not more so, once we know what we're dealing with. Younger Onset patients and families, as Darby Morhardt said, have unique needs. The affected person may be in good health and is going to need strategies for adequate long-term care and also for meaningful activities -- what does somebody do who's young and vital and who is very disinhibited and can't stay at home and is not well enough to go out and be on their own. And then of course there are quality of life issues.

Next slide.

I would like to advise those of you who serve individuals with Early Onset Dementia to talk to their doctors but to be equipped with information because most general practitioners lack information about Young Onset Dementia. So one thing that you can do is to educate people about the possibility that these conditions do exist and to try to enlist the assistance of their primary care physician to get the proper care.

Request neuropsychological evaluation, preferable at a specialty center, but if none is available, you can contact AFTD and they might be able to locate more regional services and give you some guidance.

If a PET scan is available, I would definitely ask for one, if I had a relative that was suspected of having Frontotemporal Dementia -- especially if all the other tests have been negative or normal. All of these Frontotemporal Alzheimer's, all these disorders you can have an entirely normal MRI scan because the structural changes in the brain are at the cellular level. You don't see them on what is really what amounts to an x-ray of the structure of the brain -- which is an MRI scan -- so request a PET scan if it's at all available.

And then request a repeat examination in 6 to 12 months. Very often individuals with Younger Onset Dementia who may have a behavior disturbance will score normally on the tests that they're given. But because the dementia is progressive, when you see them in six months or in 12 months they will begin showing signs of decline and sometimes you don't pick it up on the first examination -- which is very frustrating.

Next slide.

What happens with time? What does the future hold for someone with a diagnosis of Young Onset Dementia? Next.

What I've done here is to compare three primary types of Early Onset Dementia -- the behavioral variant, the Primary Progressive Aphasia and the memory dementia of the Alzheimer type. And I've listed here some of the very earliest symptoms. So now here we're talking about early stage symptoms of Early Onset Dementia.

And in the early stages we see the greatest differences between each type and each other type. So in the behavioral variant, it's all behavior. In the PPA variant, it all has to do with word production. And in the DAT variant, it has to do with forgetfulness and short-term memory loss.

But as these diseases predict, and by the way we don't know how long the entire course of the disease is going to last and the rate at which symptoms will worsen, but we do know they're going to worsen, and so in these early stages you have the greatest ability of seeing these differences among the groups.

Next slide.

As the disease progresses and invades other brain regions, you start to get additional symptoms. So no matter what kind of dementia you had to begin with, by the end you really couldn't tell one apart from the other. But the big difference is the early stages. And then how long the early stages are going to last. In some people, they'll last two years. In some people, they'll last 15 years. So you have to have a different approach.

Next. Excuse me.

So the early stages can last for many years and during that time the symptoms may just be confined to one or two functions -- language or behavior. But as the disease progresses in the brain, the symptoms are going to increase and they'll lead to more disability and eventually the individual requires full supervision and care.

Next.

We have a lot of research needs for Younger Onset Dementia. We don't know what the prevalence or incidence is or what the risk factors are, so we need a lot of epidemiology and public health studies because we don't know who's affected. We think a lot of people have been misdiagnosed and maybe people who are in long-term psychiatric facilities really have behavioral variant FTD.

We don't really understand the pathophysiology or what causes these forms of non-Alzheimer dementia. Although we have been very good at discovering these genes and the associated proteins, we need a lot more work. We certainly haven't done as much investigation of these as we have done of the pathological features of Alzheimer's disease.

We don't know what we should target for drug development and that sort of in part depends on Item 2 on this list -- what are we going to target. Are we going to target the TAR protein, are we going to target some other kind of a protein, are we going to not look at the proteins, are we going to make some other sort of attack? So we need to have a lot more basic science information about what medications can we design to solve what problem in the brain.

We need behavioral interventions. We need to help patients and families who are coping with these tremendous changes in their lives. And as Darby

Morhardt mentioned, the Social Security Administration Compassionate Allowance list has gone a very long distance in helping us work with patients and families who need help and need relief now, not in two years from now.

Next.

I just wanted to turn your attention to this booklet that we were very happy to work with the National Institute on Aging, the Association of Frontotemporal Degeneration.

Next slide, please.

And I believe there are more people to be acknowledged who really contributed a great deal to the creation of this booklet that tries to explain the frontotemporal degenerations, the various subtypes. These are really wonderful to give out to families, and we're very delighted that the National Institute on Aging helped us create - well got us together to create this and to make it available. It really is very good to be able to share this with people who need information.

Next.

These are my collaborators at Northwestern. On the left side extramural, we collaborate with people around the world, our students and post-docs, our staff and the PPA project people. And our motto for our center is "From Cells to Social Work," because that's really the only way we're going to attack these devastating disorders.

Next. Thank you.

Amy Wiatr-Rodriguez: Great. Thank you so much, Sandy. And we've got a ton of questions that are coming in through the chat feature -- which is great. We're going to take just one right now, one that came from Joanne. And she's asking, "What can a family do to get an autopsy to confirm the type of dementia -- particularly in rural areas or those lacking funds?" I don't know if that's something you can answer.

Dr. Sandra Weintraub: Yes. It's a big problem. At our center we do brain autopsies, but we will only do them on people that we have followed during life. So the autopsy is valuable to the scientist only if there has been a very straightforward clinical examination and the person has been followed throughout all the stages of their illness so that we know that they had this illness.

We do get requests from families to do a brain autopsy, but we just can't do it. We don't have the funding to do that unless they've been in our research, and the research funding helps support those activities.

So what I would suggest is if somebody knows a family, and we have a network of 27 centers around the country, we could try to put them in touch with the closest center, and see if there's some way of getting them followed so that they can get a brain autopsy, and they can get genetic testing if that's at all indicated.

Amy Wiatr-Rodriguez: All right great. Thank you so much. And again there are more questions and comments coming through. Some of you have mentioned some resources or upcoming events. I'll try to post those in the chat feature. And right now though we're going to have Sharon Denny, who is with the Association for Frontotemporal Degeneration, talk about the resources and

service delivery for people affected by Younger Onset Dementia, so go ahead, Sharon.

Sharon Denny: Thanks very much, Amy. And I just want to echo the appreciation of our other presenters today that it is wonderful for our organization to be part of this event because there's such a tremendous need for additional attention to these diseases and especially Frontotemporal Degeneration -- which by virtue of the different symptoms and the younger onset really does separate families and their experiences from those people who are tackling the older dementias.

Next slide, please.

So our organization really was created out of this need to have specialized services to address the needs of these families. And our entire approach to these services is driven by the experience of families and that's the angle that we have come from and the angle that we continue to promote in all the aspects of our mission.

So one of the things that I wanted to echo in terms of what Dr. Weintraub said is that the experience of families in this realm of dementia is really quite different and it's defined entirely by the difference in the symptoms, because these are symptoms that change the behavior and personality and language that are not what people are expecting when they think of in terms of dementia. And so you do have a person who's younger and healthier looking and a family that's reaching out for services and the lack of the understanding of the disconnect is one of the things that truly characterizes their experience.

So I'd like to actually have you turn the clock back about 35 years, because in 1978 when Craig Comstock, who was a math professor at Stanford, was diagnosed with FTD at the age of 44 there really were completely no services.

He had to - there actually weren't services even in any of the areas of dementia the way we have them now.

And Craig Comstock soon had to stop working because of these symptoms of the disease -- which included impaired judgment and behavioral problems - and the need for supervision that he had caused his wife to stop working as well and become a full-time caregiver.

They had a daughter in college and two sons in high school and there really weren't any services at all. So Craig's wife, Helen-Ann Comstock, on her own developed a support program really with the help of about 25 to 30 volunteers that they collected on their own from friends, families and colleagues. And they became a well-organized army of volunteers. And through this experience she learned what was necessary to create a network of care and support when someone's facing FTD.

Seven years later after his death, she became much more involved in advocacy and served for 15 years as the first Executive Director for the Southeastern PA chapter of the Alzheimer's Association.

But her personal interest in FTD from her experience with her family remained very keen. And two years after her retirement from the Alzheimer's Association and at the urging of other caregivers and researchers she founded the Association for Frontotemporal Dementias -- which is now called the Association for Frontotemporal Degeneration. And the goal of this organization was to continue to promote the need for shining a spotlight on FTD and developing more services for these families.

Next slide, please.

So the mission of the organization is outlined here on this slide. And what you'll see is that there's a focus on advancing care and cure together. So the mission includes promoting and funding research, providing information, education and support, educating physicians and health professionals, increasing public awareness, advocating for long-term care and social services and facilitating the international exchange of ideas.

Next slide, please.

So information empowers families, and regularly we have people call to say they were given a diagnosis of Frontotemporal Degeneration or one of the disorders and told that there's really no treatment and there's nothing that we can do. So people need to go home and get their affairs in order, and they're not really given much else by way of information or interventions and things that they can do.

So the information that Darby Morhardt shared with us are all things that are beginning to filter out through the systems but which need additional attention and fostering in order to really take root.

So one of the aspects of this is that information that is specific to FTD is necessary across the spectrum, so it's for families as well as for providers. So general dementia resources are very applicable in many ways but they're really not specific to the experience of people who are faced with symptoms of behavior and personality changes or loss of language in the ways that were described earlier.

So it really is in areas where FTD differs from Alzheimer's disease where families are left confused and feeling marginalized in terms of the care and the resources that are available to them.

People need guidance for managing care. There's a huge amount of caregiver energy that's spent researching, searching for and handling the logistics of all their changing circumstances day to day. And anything that we can do that's going to help them to shorten the amount of time that they spin their wheels looking for resources will enhance their ability to actually use those resources and make changes that are going to benefit themselves and their families.

They're also in need of finding resources that are specifically experienced in working with people with FTD. And there's a growing base of organizations that are becoming aware of the differences in the types of dementia and beginning to respond. But the interventions necessary to handle folks with these different types of symptoms are critical and finding resources remains very difficult.

So our organization works to try to connect the experts and the emerging research that you heard about earlier, as well as providers on the ground in the communities to help folks be able to find services and the resources that they need.

So some of the ways that we do this include our Web site -- which just by way of context, you know, AFTD's Web site really is our front door. It's how people find a lot of information about both Frontotemporal Degeneration and what's available to them.

And we're now finding we have about 16,000 visits to the Web site every month and about 11,000 unique visitors a month -- which gives you a sense of numbers and that while we're talking about disorders that are not well known still there are a lot of people looking for information and a lot of people who need this information.

We have a newsletter that goes out to 4000 people in print three times a year and about 4600 electronically. So again there's a strong base of interest in information needed in these disorders.

And then you'll also see here some other publications that we have collaborated with experts on in order to begin to address some of the very particular needs that people face. The Frontotemporal Disorders booklet was mentioned. The green booklet next to that is one we've done recently for folks who are facing a new diagnosis of FTD. And this is again part of the effort to provide some guidance for folks in those earlier stages.

What About the Kids? is a booklet that addresses the needs of families where there are children at home and a parent who's diagnosed. And again some of the particular hardships people face when they're confronted with behavior changes, bizarre behavior and lack of judgment in a parent and they have children who are still living in the home.

And the last one you see was a collaboration with partners from the University of Pennsylvania and that specifically addresses the genetics of FTD -- which Dr. Weintraub mentioned is a particularly complex aspect of these diseases. And so to try to make information available that's a bit more lay language for folks is one of the goals of this information that we share.

Next slide, please.

We also know that support encourages strength for the caregiving journey. And as was mentioned earlier, there is a higher burden of care that families face when the diagnosis is of a younger person and when the symptoms -- particularly behavioral symptoms -- are part of the picture.

There's a tremendous risk of isolation among families who are facing these diseases between the combined storm, if you will, of all the needs day to day and the lack of understanding they find among providers and family and friends. So we provide various services that will enable people to find support and connect with people who understand their experience and can provide some sustenance for the journey.

A helpline, an individual helpline allows people to call and get specific responses -- either by phone or by e-mail. We handle about 150 questions to that helpline every month through our program staff here at AFTD.

We also offer some phone groups for people in order to connect with other caregivers. And again some of those are for particular needs within our community -- both for the young families where there are people who have a parent diagnosed and kids at home. And we're also just recently starting a group for people themselves who have been diagnosed with FTD. We have a phone group now for support for those folks as well.

We network a group of - we provide a network of support to the facilitators of FTD groups across the country again to continue that education and to foster what resources can be funneled to the members of those support groups.

We do some individual connections for people who want informal contact with other FTD caregivers. We support and sponsor conferences, like what Darby mentioned, that are specifically around FTD and PPA. And each year, AFTD presents its own education conference -- which really tries to maximize the opportunity for people to come together as a community of folks who understand this experience that they share.

And we provide some specific financial assistance in very modest amounts but to encourage people who are full-time family caregivers to use respite and to access some additional travel help to get to one of these education conferences so that we can help them to continue to learn what they need to improve their confidence and their skills as caregivers.

Next slide, please.

So education has also been mentioned earlier today in terms of the importance of educating our provider community. And we've been expanding what we're able to do there as well. We have a very dedicated core of medical advisory council members who come from a lot of those centers that you saw listed as the ADRCs and other places where we have folks focusing on Frontotemporal Degeneration.

Where possible we partner with them for accredited trainings that offer CMEs to physicians. We've also done an extensive amount of outreach to other professional groups across all the disciplines through articles in nursing journals. We just completed a webinar series for people who are speech and language pathologists to learn more about PPA and that was another example of collaboration being able to bring together and create new resources in this way.

We've done trainings for the National Adult Day Services Association and we have worked with colleagues in hospice again to try to bring specific FTD information into those provider communities.

We have information on our Web site for health professionals again developed in concert with our experts, the folks on our Medical Advisory Council, so that we can make sure that what we're offering is accurate and

current. But that is a section that provides some quick access to professionals who are looking for a little bit more clinical information about these disorders.

Next slide, please.

One thing I'd like to highlight here is an initiative that we call Partners in FTD Care and this truly is developed to provide education for community providers, facilities, day programs, home health agencies. We're using - we have a committee of wonderful, seasoned experts in various areas of dementia care, FTD, social work and education and we are producing regular case-based studies that will bring to light different aspects of these diagnoses as well as very practical, hands-on interventions.

So these are available through electronic delivery by newsletter on a quarterly basis, as well as we've developed a packet of initial materials that people could use for introductory and service trainings. And we also have an online interactive forum that we're developing so that people can share their successes in working with and developing interventions around FTD behaviors and needs, as well as to share with other providers who are also interested in this aspect of the field.

Next slide, please.

And so research drives progress. We know that research and care need to advance together and especially when we're talking about a community that is somewhat limited by its numbers that, you know, we need to have the strongest partnerships that we can in order to make progress across the realms of research and care.

So one way that our organization does this is money - that we do raise money and devote money specifically to research in FTD and areas of research that are going to hone further our understanding of these diseases and begin to target treatments within them.

So each year for example we do a pilot grant that is awarded to try to do a seed study that can be parlayed then into some additional work down the line. And the most recent round of that pilot grant had submissions from over 40 investigators in the U.S., across the U.S. and internationally as well.

We also partner on a drug discovery effort where donations to our organization from people who want to target their money in this way are matched two to one by a partnership with the Alzheimer's Drug Discovery Foundation in New York. And they go specifically to grants awarded in the area of drug development and drug discovery.

We also know that having people who are interested in these diseases is very important and so we fund a fellowship -- a two-year fellowship -- every two years for a young investigator who is devoting their career to learning about these particular diseases. And it's one way that we can encourage them, encourage more people to follow along and particular attention to this part of the neurodegenerative disease spectrum.

So we work a lot through partnerships to try to leverage the resources that we have and keep the focus on FTD.

One thing that's becoming more important critically as the research does move forward and we're beginning to identify potential targets for treatment conducting clinical drug trials in FTD is very challenging. It's challenging for the studies to be designed. It's challenging for them to be executed and part of

that is to make sure that families are aware of opportunities, that they know how to evaluate the opportunities and that they are able to make good decisions for themselves about their participation.

So AFTD has begun an effort to really educate and empower families to understand clinical trials and be able to recognize the importance of this partnership moving forward that it really is only through people being able to participate in studies that the researchers will continue to learn and be able to develop treatments that we all long for.

Next slide, please.

So just to sum up I just wanted to highlight that there's tremendous value in being able to offer specialized resources within an area of specialized need. And when we're talking about the Younger Onset Dementias and specifically Frontotemporal Degeneration with its unique set of symptoms, we know that services and support do need to be tailored in order to meet the needs that the community presents.

So through having an advocacy organization dedicated to these particular diseases we're able to create a community that brings people together from across the different clinical presentations and the different diseases but can add strength by uniting together in numbers. We also create then a hub for that cross-disciplinary collaboration that's going to bring expertise from all the different areas together and be able to focus it on moving services forward for the folks in this community.

We create opportunities for people to get involved, whether they're investigators and researchers or family members who want to volunteer or professionals who are looking to expand their own career paths and

knowledge base. We're able to address those needs within the particular interests of the FTD community.

And then ultimately what we see is that by having specialized resources and a focus on a particular set of needs, we are able to leverage our resources and create change and make things better for the future. So thank you.

Amy Wiatr-Rodriguez: Great. Thank you so much. And I may have sent out a message on the Web chat, Sharon, with the wrong number for the helpline. Is the prefix 866 or 877?

Sharon Denny: 866.

Amy Wiatr-Rodriguez: Okay. So I have it wrong on the slide. We'll correct that and make sure that that gets updated. But it is 866-507-7222, correct?

Sharon Denny: Yes. Thanks.

Amy Wiatr-Rodriguez: Okay. Great. Wonderful. Well thank you so much and we have just a couple of minutes for questions and we are getting - we have so much coming in and we also want to try to take some on the line. So if our operator could come on and let people know how they can ask their questions on the phone and then we'll try to get some of them that came in through Web chat too. So, Kathy?

Coordinator: Thank you. If you'd like to ask a question on the phone lines, please press star 1. Be sure to record your first and last name. To withdraw the question, press star 2. Once again star 1 to ask a question.

Amy Wiatr-Rodriguez: Great. And while we are waiting for that, we've had a couple of questions come in around Social Security Disability from several people, Serena, Shelia and some others. And one of the questions was, "If people don't have the 40 credits built up, is that something that they still would qualify for the Compassionate Allowance assistance?"

Darby Morhardt: This is - they need to actually qualify for Social Security Disability Insurance, so that's first and foremost. Are you able to hear me?

Amy Wiatr-Rodriguez: Yes.

Darby Morhardt: Okay. Great. And so unfortunately if they don't qualify or don't have enough hours or units, then they would not qualify for it. The Compassionate Allowances Program is really just to fast track those who are eligible to get them to move faster through the system.

Amy Wiatr-Rodriguez: Great. Thank you. Kathy, do we have any questions coming in on the phone line?

Coordinator: We do have a question on the line. Jeanne Lee, your line is open.

Jeanne Lee: Aloha. I am a person with dementia of the Alzheimer type so far. I know that those change often. I know that there are many, many, many people out there who would like to speak on our behalf when these things are going on. We do have a lot to say and actually everything is not learned from books. Does anybody want to include us? Thank you.

Amy Wiatr-Rodriguez: This is Amy, and thank you very much for being on the webinar and for your comments. I don't know if any of my other - any of the other

presenters have anything that they'd like to say on kind of how they include and work with and have people with dementia involved in efforts like this.

Jeanne Lee: Yes. Thank you.

Darby Morhardt: Yes this is Darby. And I've been running early stage groups for the past 15 years and it has been an incredible opportunity to really hear the voice and to give a forum for people with this illness to talk about their experience. Everything and yes unfortunately this webinar and the short time that we had did not allow for a person with the illness to participate.

But I can assure you that the information that I particularly presented is all that I have learned from not only persons with the illness but from their families as well. So the voice is represented but I think your point is well taken that a lot of times there isn't always the opportunity given for people to express themselves directly.

I know that it sounds like the Association for Frontotemporal Degeneration is starting a group for persons with FTD.

Jeanne Lee: Yes.

Darby Morhardt: And also I know that the Alzheimer's Association has had an early stage advisory board for several years. So there are different opportunities in various organizations around the country, so perhaps if we can talk offline to discuss where those opportunities are.

Jeanne Lee: Wonderful.

Amy Wiatr-Rodriguez: Thank you so much, for both the question and Darby for your response. I know we're right at the time that we're supposed to up, but we do have so many other questions and other comments out there. So for those of you that can stay on, we'll try to stay on for just a couple more minutes to get to some of these other ones.

Let me take one other comment or question from Michael. He was asking if there's any comment that anyone would like to make on the challenges with getting insurance companies to pay for PET scans or other types of testing to understand diagnosis. I don't know if any of you would like to comment on challenges with that or if there are any things that your organizations are able to do to help people when they're trying to navigate through that.

Dr. Sandra Weintraub: Sharon, do you want to talk about that?

Sharon Denny: Well I appreciate the question. Yes this is Sharon. And so this is a challenge that we know many families face, and I'll ask my clinical colleagues to weigh in. But it's my understanding that the argument can be made for use of a PET scan -- particularly in the differential diagnosis of FTD and Alzheimer's disease.

Now that doesn't mean then that always happens easily or smoothly. One of the things that we know families routinely need to hone their skills in is advocacy on their own behalf. And so to the extent that our organization can support that with information to make that a little bit easier, we do that across the board.

In terms of the particular steps, I would actually yield to the Northwestern folks and see if in your experience you've had success with certain advocacy within your own right for getting those covered.

Dr. Sandra Weintraub: Excuse me. This is Sandy Weintraub. We have been able to order PET scans in individuals where the clinical diagnosis of bvFTD is made but there's absolutely no positive other biomarkers. So the MRI is normal or it shows a little atrophy in the frontal lobes, all the blood tests are normal and so we have been able to order a PET scan.

Now some insurance policies may be more difficult to deal with than others, as you say. But I don't really recall that we've had any requests turned down, except maybe one.

Amy Wiatr-Rodriguez: Great. Thank you. Let's go to Kathy, our operator, now and see if there's anybody else who's on the line to ask a question.

Coordinator: The next question comes from Dan. The line is open.

Dan: My question is, is it common for Alzheimer's type dementia and frontotemporal dementia symptoms to present in the same person?

Dr. Sandra Weintraub: Unless anybody else would like this one, this is Sandy Weintraub, I can take it.

Any symptoms can present in any person and any group of symptoms can present in any person related to one underlying disease and that's what makes it so difficult for us as clinicians to make a diagnosis solely on the basis of the clinical examination.

So it's actually possible to present with short-term memory loss and have FTD in the brain cells or it's possible to have a bvFTD dementia and then a postmortem autopsy to find Alzheimer neuropathology. It's rare. It's much

more common to find that for example behaviors associated with FTD pathology and memory loss with AD pathology but it's not 100% accurate. So definitely a person can have personality problems, short-term memory problems, language problems and have a single disease, not multiple diseases.

Having said that it's also possible, not too common, to have different diseases present in the same person even at brain autopsy. So you have somebody with two kinds of pathology but it's not all that common.

Dan: Thank you.

Dr. Sandra Weintraub: You're welcome.

Amy Wiatr-Rodriguez: Great. Thank you. I think maybe we'll do one more question on the phone line and one more question that's come in via chat, so, Kathy?

Coordinator: At this time, I have no further questions.

Amy Wiatr-Rodriguez: Okay. Great. So some other questions or requests for comment that came in from Mary and I know that at least one other person had asked about this was individuals with Down syndrome or other types of intellectual or developmental disabilities may also be people who are experiencing dementias with a younger age of onset and if there's any comment that those of you who are panelists on this presentation would like to make on, you know, services to those folks.

And just a reminder to everyone who's on this call that we did a special session specifically focused on persons with intellectual and developmental disabilities and dementia back in June. All of those materials are posted at the link that is on the slide that is currently up right now on the WebEx. And you

can find all those materials there, as well as you can register for our upcoming webinar next month on advance-stage dementia and palliative care.

But again back to the topic of younger folks with Down syndrome or other developmental disabilities that may be experiencing Younger Onset Dementia, would anyone like to comment on that?

Darby Morhardt: Well this is Darby Morhardt. I would refer to my colleagues who are working in developmental disabilities. It's not area of expertise for me and so I would highly encourage you to do exactly what Amy directed you to do is to go to that webinar. And persons with developmental disabilities tend not to make their way to our clinical setting, so it's an area that I have not gained knowledge and expertise.

Amy Wiatr-Rodriguez: Great. And is this a population, Sharon, that AFTD has any experience with or folks coming to with those types of concerns as well?

Sharon Denny: You know, we have not. And it's my understanding that to date it's really the Alzheimer's world that has been working with that subpopulation. It's something we'll certainly be alert for, but it's not anything we've had any experience with, so like Darby I would yield to colleagues there in the developmental disabilities world.

Amy Wiatr-Rodriguez: Okay. So it sounds like that, you know, obviously in our webinar back in June we talked about all of the issues there and it sounds like, you know, as with this topic here too there's still so much collaboration that needs to occur and work that we need to do to better improve the services and understanding for folks who are affected in that way.

Nina Silverberg: Amy, this is Nina Silverberg from NIA. We can also follow up. If the person has more specific questions, we can connect them maybe with somebody with more expertise in that area.

Amy Wiatr-Rodriguez: Okay. Great. Wonderful. All right and finally we'll just end on this one last question -- which seems to come up in all of the different webinars that we've had, and I think it just further goes to outline how much confusion and concern there is around the area.

Mona asked about memory exercises and if there's anything to show that they are truly effective in preventing any type of dementia. So I don't know if any of our panelists or, Nina, if you'd like to comment on that.

Nina Silverberg: Sandy, are you still on?

Dr. Sandra Weintraub: Yes I am. I was about to chime in.

Nina Silverberg: All right go for it.

Dr. Sandra Weintraub: So if you, you know, the teaching is that if you keep your mind active that you can slow the rate of progression of cognitive changes. And this is true not only for dementia but also for just the normal age-related effects of, you know, what you normally experience in the course of memory changes with aging.

And it doesn't seem that there's any single activity or a single game or a single thing you can do, but just it seems that people who maintain mental exercise may be at lower risk for developing dementia.

I think the strongest relationship has been between exercise and cognitive change and the strongest evidence for a positive effect on your cognitive abilities is between exercise.

But I know that there are a lot of people who are advertising brain games and exercise your mind and in fact if you, you know, as people get older, they tend not to use their mind as much -- especially if they retire and they don't have anything to fill their retirement with. So kind of trying to keep your mind as active as possible you may want to use these games but card games, jigsaw puzzles, anything that kind of keeps your mind going and solving problems is good.

Amy Wiatr-Rodriguez: All right. Well with that I want to again thank all of our speakers and especially thank everyone who joined our call today and those of you who asked questions or made comments. If we didn't get to them, we will follow up with you. And if you think of any additional questions or have suggestions for future webinar topics or especially if you'd like to share feedback with us on whether you thought this webinar was helpful or not or suggestions you have to make any of our events better in the future, we do want to hear from you.

You can e-mail us at my e-mail address -- A-M-Y-dot-W-I-A-T-R-@-ACL-dot-HHS-dot-gov. And again please share your questions and feedback with us.

We will send an e-mail out to everyone who registered for today's webinar when the recorded materials are available on our Web site. Again a reminder to please sign up if you'd like to participate in our final webinar in this series on advanced stage dementia and palliative care. It will be at our new date of Tuesday, September 24 and the information is there to register.

Again thank you for joining us and we look forward to having you with us on future events. This concludes today's webinar.

Coordinator: Thank you. This concludes today's conference call. You may disconnect at this time.

END