Zoom In on **Dementia & Alzheimer's**

TRANSCRIPT

Lewy Body, Alzheimer's & Mixed Dementias Explained

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Featuring: James E. Galvin, MD, MPH

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Please note: This transcript has been edited for clarity and brevity.

NANCY KEACH: Welcome, everybody. It's so good to see everyone. From BrightFocus Foundation's Alzheimer's Disease Research program, I'm Nancy Keach, and welcome to the 45th episode of Zoom In on Dementia & Alzheimer's. This program is generously sponsored by Lilly, Biogen, Eisai, and Genentech, and we are very grateful to these sponsors for making these free programs possible.

Today's program is Lewy Body, Alzheimer's, and Mixed Dementias Explained, and I'm delighted to introduce today's guest expert. There's nobody better on this. Dr. James Galvin is professor of neurology and psychiatry and behavioral sciences at the University of Miami, Miller School of Medic-ine. He is the founding director of the Comprehensive Center for Brain Health and director and principal investigator of the Lewy Body Dementia Research Center of Excellence. Dr. Galvin is principal investigator on nine active NIH grants. So he is the guy. He knows what new diagnostic tests and treatments are in the pipeline for these disorders. Welcome, Dr. Galvin. It's great to have you.

DR. JAMES GALVIN: Thank you, Nancy. Glad to be here.

NANCY KEACH: I'm going to jump in with a little lightning round because there is a lot of confusion about these conditions, the terminology used to describe them, and methods to distinguish and properly diagnose them. So before we jump into the questions that you all have submitted: Dr. Galvin, real high level, what is dementia?

DR. JAMES GALVIN: Dementia simply means there's a change in someone's memory or thinking function that interferes with their everyday activities. Dementia is not a diagnosis. It's the problem. The diagnosis are the specific causes of the disease.

NANCY KEACH: And what are the different causes of dementia? And why is it important to know them?

DR. JAMES GALVIN: There are over 150 different causes of dementia. And the reason it's important to know that is because we approach each one a little bit differently. There are some causes that are reversible. So for example, if someone has thyroid disease, and their thyroid isn't working, they could have dementia. But replacing their thyroid hormone could reverse that cause. And then there are the neurodegenerative diseases, the primary brain diseases, like Alzheimer's and Parkinson's and Lewy body dementia and vascular dementia. And it's important to know the differences because, again, treatment options are going to be different, and participation in clinical trials is going to be different.

NANCY KEACH: What are the features specifically for Alzheimer's disease?

DR. JAMES GALVIN: Alzheimer's is the most common cause of dementia. And this is primarily a memory disorder. So people have a change in their memory. They may have a change in other cognitive domains-- language, executive function, attention. It progresses over time. But what's interesting is the neurologic exam. The physical exam of patients with Alzheimer's disease is relatively normal. And so they don't have any focal findings, and it has biomarkers, things we could measure in the blood or on imaging studies that can tell us the presence of the plaques and tangles that are part of the disease. So we make a very, very specific diagnosis, and we have the most tools available today for making the diagnosis of Alzheimer's disease.

NANCY KEACH: And what is Lewy body dementia? And what are its features?

DR. JAMES GALVIN: Lewy body dementia is a less common cause of dementia, about 10% of all cases, about a million and a half people in the United States. It's really a group of two different diseases. One is Parkinson's disease dementia. That is, someone starts out with the motor signs of Parkinson's disease and then later develops the cognitive and behavioral symptoms.

And then there's dementia with Lewy bodies, which starts the other way. People have cognitive and behavioral features and may or may not develop some Parkinson-like features. They both have Lewy bodies. That's the change in the brain, the small clump of protein that forms inside the cell. That's Lewy body, and that's present in both forms of Lewy body dementia. The primary features are a change in cognition typically more visual, spatial, perceptual, executive attention, maybe a little less memory early on. They can have signs of Parkinson's. So slowness, stiffness, tremor, balance problems. They have visual hallucinations, hearing or seeing things that aren't there. They have

fluctuations. These are spontaneous changes in alertness and attention that come and go like a light switch. And they can have something called REM sleep behavior disorder that's acting out their dreams. So they need at least two of those features to make a diagnosis.

NANCY KEACH: And finally, last question of the lightning round, what is meant by mixed dementia?

DR. JAMES GALVIN: So mixed dementia means there are two or more things going on in the brain that can explain the symptoms that people are having. Typically, doctors will make the diagnosis based on the symptoms that seem to be the most prominent. So you can have changes of Alzheimer's disease and changes of Lewy body disease. You can have changes of vascular disease and changes of Alzheimer's disease. The clinical diagnosis may be based on which of those changes is causing the symptoms that are apparent to you. But truthfully, we mentioned this off camera, is that mixed dementia actually is probably the most common cause of dementia. We just don't make that diagnosis because we don't necessarily know those other things going on. We don't have ways of measuring them.

NANCY KEACH: Yeah, and we were talking about this before we came on, that, in fact, we're making tremendous strides in the research today on diagnosis and even on some treatments. But as we develop biomarkers for each of these specific causes of dementia, we tend to talk about them as if everybody has one. You have this or you have that. But actually, Richard Isaacson had said it to me first when we were talking about Lauren Miller Rogen's mom, Seth Rogen's wife's mom. He said, well, I think she had lots of mixed, and I think that's more common. So you agree this is it's more common to have some combination than one or the other or the other.

DR. JAMES GALVIN: Yeah, so people come to autopsy. They have their brain examined after they pass on. Most people have more than one thing going on, and many people will have two or three things going on. But again, they may be silent in terms of causing clinical symptoms, but they contribute to what's happening to that person in life.

NANCY KEACH: I'm going to go now into the audience questions and some commentary. So I guess it was about eight years ago, I met Susan Schneider Williams, Robin Williams' widow, who is really lovely. And I cannot forget, since this is the first time we're talking about Lewy body on this program, her incredible grief that Robin was misdiagnosed with Parkinson's initially when he really had Lewy body disease and how frustrated he was that he and she was that they knew they didn't quite have the right finger on what was causing his changes and her feeling, was-- that in some ways,

that misdiagnosis may have some ways contributed to his suicide. And I'm going to put up at the end of the episode an incredible op-ed she wrote called "The terrorist inside my husband's brain" because I think it's still one of the most powerful arguments for why it's so important to get an accurate diagnosis in these diseases or as accurate as possible.

Kim, from Phoenixville, Pennsylvania wrote, "A family member was diagnosed with Parkinson's then later with Lewy body dementia. Could he have had Lewy body all along?" And Leonard from Haverford, Pennsylvania, "How can we know early whether it's Lewy body or Parkinson's?" And so I'm going to ask you to answer those. But I'm also going to start out with this from Lawrence in Maitland, Florida, "Explain to me, what is or are a Lewy body or Lewy bodies."

DR. JAMES GALVIN: Lewy bodies are the clumps of abnormal protein that are inside the brain cells. They're made from a protein called alpha-synuclein. Now, we don't know what alpha-synuclein does, but it seems to be very important for normal cell function. And so alpha-synuclein clumps together to make a little round inclusion inside the brain cells. That's a Lewy body. That was originally described in the brains of people with Parkinson's disease. So Parkinson's disease is a Lewy body disease.

Parkinson's disease may or may not develop dementia. When Parkinson's disease develops dementia, that's a Lewy body dementia. But there are also people who develop Lewy body dementia that don't have Parkinson's features, and they can have other symptoms the hallucinations, the delusions, the fluctuations, all those things we talked about before.

So Lewy body is the pathology or abnormal change in the brain. Parkinson's disease has Lewy bodies, but they may not have dementia. So if someone starts out with motor Parkinson's disease, that may be the correct diagnosis. But about 80% of people with Parkinson's disease can go on to develop a dementia that's a Lewy body dementia.

NANCY KEACH: From Hugh in Lincolnwood, Illinois, "How does the Lewy body present itself." I guess you mean symptomatically in patients initially? "And also in what time frame typically can you recognize those specific symptoms?"

DR. JAMES GALVIN: The symptoms can occur in any order whatsoever. And what's interesting about Lewy bodies, they're not just found in the brain. They're found throughout the nervous tissue in the body. So you can find them in the walls of the colon, the walls of the bladder, the walls of the heart, in the sweat glands, in the salivary glands, in your sebaceous glands that moisten your skin. People can have lots of different symptoms, and they don't know that these are going on or caused by this.

So for example, many people who develop Lewy body diseases may have had 20 years of constipation. They may have urinary retention. They may have sexual dysfunction. They lose their sense of taste and smell. They have abnormal heat regulation because they don't sweat the right way. They may drool. They may have a runny nose. Now, people say, well, I don't know what that means. I don't know what that is, but I've had that for 20 years. Then they develop the symptoms of the disease that we more classically describe when the disease is affecting the brain, movement changes, slowness, stiffness, a rest tremor, behavioral changes, hallucinations, hearing, or seeing things that aren't there, fluctuations, these spontaneous changes in alertness and attention that switch on and off from minute to minute, second to second, hour to hour, REM sleep behavior disorder, acting out dreams.

So all of these things can appear, but they appear at different times, and not everybody will have everything. It makes it a very difficult diagnostic challenge. There's the old expression, three blind men in a room all touching a different part of the elephant, and they're all thinking it's something different. Depending on each person, they can have a very, very different mixture of presentations. And depending on who you show up to first for care, you might get a different diagnosis with eventually someone putting it all together.

NANCY KEACH: And this is going to lead later, we're going to talk about new technologies to diagnose Lewy bodies. So there isn't a specific set of symptoms that you could look for to say, ah, this is Parkinson's? This is Lewy. It's not as straightforward as that.

DR. JAMES GALVIN: So Parkinson's disease is the motor the motor features. Rest tremor, slowness, stiffness, balance problems. That's Parkinson's disease. The broader Lewy body dementia has the dementia that they have to have a cognitive problem, and then at least two of four core features Parkinsonism, hallucinations, fluctuations, and REM sleep behavior disorder. To make the diagnosis of Lewy body dementia, you have to have dementia plus at least two of those clinical symptoms.

So you can make it. But you have to ask the right questions. People don't know to tell you that they're fluctuating. People are afraid to tell you they're hallucinating. And people don't know they're having REM sleep behavior disorder because they're sleeping. Only the bed partner can tell you about it. So this is why it's sometimes very hard to make a diagnosis. And it occurs later than you would have liked.

NANCY KEACH: And it's why we do these programs to try to help more people know what to ask and more doctors know what to ask as well. Julie from Ontario, Canada

says, "To what extent are Parkinson's and Lewy body dementia linked to genetic versus environmental risk factors. Do we know, are the causes for this genetic? Are they environmental? Are they both? Do we know?" Kenneth asks, "If you have three, four APOE gene makeup, does that make you more prone to getting Lewy body dementia?"

DR. JAMES GALVIN: So Lewy body dementia are largely sporadic. They occur randomly in the population. So we don't know what the underlying cause is in most people. There are some studies looking at environmental factors, and there are some genetic risk factors that have been identified. So there are rare, very, very rare mutations of that alpha synuclein gene. Very, very rare. And then there's a mutation in a gene called GBA, which is glucocerebrosidase. This is an enzyme that metabolizes fats in the brain. And it's more prevalent in people of Ashkenazi or Eastern European descent. If you have two copies of this mutation, you get a pediatric disease called Gaucher's disease. But if you have one copy, you're more likely to get an adult disease, which is Parkinson's disease or Lewy body dementia. But again, that's a small portion of the patients. Most patients, we don't know what causes it.

NANCY KEACH: Kim from Norfolk, Massachusetts, "How common are co-dementias?" I know you talked a little bit about the relative Alzheimer's incidents to Lewy body. Do you want to break it down between Lewy body Alzheimer's, Parkinson's, FTD, vascular, that kind of breakdown?

DR. JAMES GALVIN: If you're trying to identify the single cause, Alzheimer's is the most common single cause. We used to say about 60% of cases are due to Alzheimer's disease. The Lewy body dementia are about 10%. The vascular dementia are about 10%. The frontal temporal degenerations are about 10%. That's close to 100% right there. All those other all those other conditions together make up a very, very small proportion.

But what's interesting is, again, many of these diseases coexist. People diagnosed with Lewy body dementia, about 80% of them will also have Alzheimer changes. Of people diagnosed with Alzheimer's disease, about 30% of them will have Lewy bodies. For both Alzheimer's and Lewy body dementia, about 50% of them will have vascular changes in their brain. They'll have cerebrovascular disease. So very, very commonly there are other things happening in the brain, but they may not have obvious clinical symptoms associated with it.

So as clinicians, we primarily focus on making the primary clinical diagnosis and tend to be a little less worried about making secondary or mixed diagnoses if it's not presenting as a problem. As a researcher, I can measure lots of different things. So I can make mixed diagnoses very easy. But in a clinical setting, we don't have all those tools

available to us, typically.

NANCY KEACH: Two quick questions before I go to diagnosis, Nancy writes, "Does having one type of dementia increase your risk of having another?" Or more, I guess? And Cindy from Grosse Ile, Michigan, "How long is the average onset of symptoms to end of life?"

DR. JAMES GALVIN: Because these diseases can commonly co-occur, as I mentioned, not that it makes you necessarily more likely to have it because you have one that you can't get another is if they're all occurring in the brain, and we know a lot about all these diseases except why they first happen in most people.

So we know steps two through infinity. What we don't know for most people is step one. In terms of the second question that you asked, it depends a little bit on the individual. So if you've seen one person, you've seen one person. Everybody's different. Everybody has their own unique journey in these diseases. But in general, Lewy body dementias progress faster than Alzheimer's disease. So while Alzheimer's disease, from start to finish, the median, that's the 50th percentile, is about 8 to 10 years for Lewy body dementia, the median that's a 50th percentile is about seven to eight years, right. So it's a shorter duration disease because there are lots of other things happening. They have the Parkinsonism. They have the psychiatric symptoms. They have the sleep symptoms. They have the memory symptoms. It progresses faster. But it's going to be different for each individual. There are people. Six months later, that's the end of their life. And there are people living with these diseases for 20 or 30 years. So it's very hard to look at an individual and predict that.

NANCY KEACH: And before I move on, we did do an episode specifically on frontotemporal dementia. So if anybody wants to look for that specifically, it is available on our website BrightFocus.org/zoomin. But we got a lot of questions in the chat. So Cathy asks, "Currently, there are biomarkers for these two families of dementia, for example, Lewy body and Alzheimer's. What do we have for FTD or frontotemporal dementia?"

DR. JAMES GALVIN: We could have a whole program on FTD.

NANCY KEACH: Yeah, and we have, and we will again.

DR. JAMES GALVIN: There's not one disease. It's a lot of different diseases. About half of the people with FTD will have accumulation of a protein called tau protein. And so we can measure tau in a couple of different ways, but the other half have other protein abnormalities for which we have no way of measuring them at the present time. So

there is a blood biomarker called neurofilament light chain that is not specific at all. So it can be raised by anything but appears to be in the absence of other biomarkers, a potential biomarker for identifying people with FTD. But it's not quite there yet. It's not ready for prime time yet to say that. And there's lots of really exciting active research going on to try to identify markers for FTD.

NANCY KEACH: And so here's another general question that could be not only one episode but 10 episodes. Mary Lou from Palm Desert, California, "How prepared are most neurologists to recognize and accurately diagnose Lewy body and dementias?"

DR. JAMES GALVIN: On paper, every neurologist can make these diagnoses, right? Because all neurologists are trained to identify neurologic disease. And in the old days-- and I'm old enough to remember this-- neurology was the specialty that knew everything and could do nothing, right? So we knew a lot about making diagnoses, but we didn't have any treatments. That's not true anymore. We have lots of things that we can offer people that weren't available before. So in theory, all neurologists can make it. The tricky part is figuring out the right questions. So for Lewy body dementia, there are several toolkits that have been developed. I developed one called Lewy Body Composite Risk Score. The group in the UK developed the diamond Lewy worksheets, and these worksheets allow a way of asking standardized questions that enhance the ability to make a diagnosis in a relatively brief period of time.

NANCY KEACH: That's very helpful. And I'm sure helpful to neurologists because I know I mentioned Susan Schneider Williams. For a couple of years, she went to every neurology conference she could and talked about please learn to diagnose Lewy body. So are there new technologies now? I have questions from Christine in Ohio and Janice about PET scans, amyloid PET scans in particular. Can you get a blood test to diagnose this? And I know this is a lot for you to respond to. But can you use a PET scan or a blood test? And what are new technologies that are developing or developed to recognize the differences?

DR. JAMES GALVIN: For Lewy body dementia, there is no blood test. There is no imaging study at the present time. There are candidate PET tracers that are being tested, but they're not available yet. There was no blood test at the present time. So there are two diagnostic tests that are currently available in the United States for trying to identify Lewy body dementia. One is through spinal fluid. It's a seeding assay. So we draw spinal fluid through a lumbar puncture. And then that fluid is then spiked with a protein and we see it. Then if it aggregates. And if it aggregates, that tells us that there's Lewy bodies present. And that's called a seeding assay.

And then there's a skin biopsy. So remember, before, I said that Lewy bodies are actually present throughout all the bodies. So we can take a three small pieces of skin. And we look at the nerve fibers in the skin and see if there's Lewy bodies there.

Both of those tests have reasonably good sensitivity and specificity, but they're qualitative. So it's either present or absent. It doesn't give us an absolute number. So unlike amyloid or tau blood test, where you can say you have this much amyloid in your brain, we can't do that with the synuclein test for Lewy bodies. We can only say whether they're present or absent. And the potential problem with the skin biopsy is if I take a piece of here, but your Lewy body is over here, I'm going to miss it in the skin biopsy and I have no idea. So sometimes people will have symptoms, but their skin biopsy is negative. If you repeated the skin biopsy in a couple of months, it might turn positive. So a positive skin biopsy confirms you have Lewy body disease. A negative skin biopsy doesn't mean that you don't have it. It just means that there was nothing on the biopsy. So a little challenging.

Blood's going to be a lot harder to do because that synuclein protein is very highly prevalent in the blood, and it's so much there that there's really-- there's so much noise that you can't see any signal. And so it's going to be really difficult to develop a blood test. There is one company in Taiwan that's developed a blood test. It's not available in the United States yet. So we've been testing and other labs have been testing it. So we're trying to learn more about how well it can work.

Last thing I'll say about imaging real quick is that for Parkinson's disease, the motor symptoms, there is a scan that's available. That's called a DAT scan. That's going to tell you whether you likely have Parkinson's disease or not. But that's not measuring Lewy bodies. It's an indirect measurement. It's looking at dopamine, the chemical that helps you move. So when the dopamine is too low, people develop Parkinson's. And we can measure that with a DAT scan. But it's sort an indirect way of measuring the Lewy bodies because you're not actually seeing Lewy bodies.

NANCY KEACH: Thank you because we have had just two questions submitted about DAT scans. So you got there before me. I'm going to throw this in there. Well, let me first do Eileen from Ewing Township, New Jersey, "How early in the disease process can a diagnosis be made?" And yes, to everybody. I am going to get to treatments.

DR. JAMES GALVIN: So we can make the diagnosis very early. We can make the diagnosis before there are even symptoms if you happen to get one of those tests. But there'd be no reason to do those tests unless you had symptoms. But we know from research projects that we can actually pick up the changes before people have any

symptoms. So at the last Alzheimer's Association International Conference my group presented a poster about preclinical Lewy body dementia. That is, we found the disease before the person had any symptoms. And we discussed the ethical dilemma around doing this in clinical practice. So it could be done, but it wouldn't be done under normal circumstances because there'd be no reason to do those tests in someone who doesn't have any symptoms. But we can find these things very-- these things are happening in the brain up to two decades before people have symptoms. So the possibility of pushing the envelope all the way to prevention is great. That possibility is there. It's amazing opportunity. We just got to figure out how the best way to do that is.

NANCY KEACH: I'm going to move on a little bit from diagnosis to treatments. And I'm going to start with a question from Susan in Framingham, Massachusetts, "Is there a different treatment, or are there different treatments for the different types of dementias?"

DR. JAMES GALVIN: This is why making a diagnosis is so important because each dementia, you're going to take a slightly different approach because they have different symptoms. They have different presentations, and they may have different sensitivities to medications. So for Alzheimer's disease, which I'm just going to briefly touch, we have medicines that have been around for 20 years that treat symptoms of disease but don't treat the underlying disease. And we have two newer medications that were approved that remove amyloid from the brain. So those are disease modifying medications. So that's exciting. Those are new advances in Alzheimer's disease.

For all the other dementias, we have far fewer tools in our bag, and what we typically then do is borrow medicines from other fields to treat the other symptoms. So for Lewy body dementia, there's no approved therapies. So what we do is we borrow medicines. We borrow medicines from Alzheimer's disease to treat the cognitive symptoms. We borrow medicines from Parkinson's to treat the movement symptoms. We borrow medicines from narcolepsy to treat the sleep symptoms. We borrow medicine from psychiatry to treat the hallucinations. So we borrow medicines, and the challenge with a lot of this is that you treat one symptom, you sometimes can make other ones worse, because they have unwanted side effects. And Lewy body patients are very, very sensitive to medicines, much more so than the other dementias. So they can have very, very serious adverse reactions to some medications. So it's very important to make a correct diagnosis and choose the right medicine. Right medicine for the right person at the right time really is the key.

NANCY KEACH: So in doing research for this a lot of different types of medications for the different types of symptoms. I know we can't cover them all today. But since I do

have several people asking about Alzheimer's treatments and how this relates, I wonder if you could talk about some of the therapeutics that are in trials. I'm thinking just for this question about TRAILBLAZER 7, which is taking one of the monoclonal antibodies, Kisunla, that has been developed for Alzheimer's disease and testing it for effectiveness in Lewy body. Could you talk about that and then maybe some of the other trials that are going on specifically for distinguishing how the drugs will work?

DR. JAMES GALVIN: Sure. So for the donanemab, or Kisunla so about 80% of patients with Lewy body dementia also have amyloid in their brain. And so this is a trial to test for those patients who have both changes in their brain, the Lewy bodies, and amyloid, if removing the amyloid is going to provide any benefit. And so that's a trial that we'll be getting started and we're very excited to find out what happens. But that's going to take three to five years to really know the answer to that question.

Three medicines were tested recently in phase 2 studies. One was called zervimesine and this blocks the ability of an abnormal protein to bind to a cell and cause damage. There was another one called neflamapimod, and this is an enzyme inhibitor that seems to protect basal forebrain, cholinergic neurons. These are the neurons that make acetylcholine. And the third one is nilotinib which is also a kinase inhibitor, and this was a drug that's been used to treat rare forms of leukemia for a long time, but may be protective of dopamine neurons in the brain.

So these three medicines were tested in patients with Lewy body dementias. And they had good safety signals and efficacy signals. They're going to move forward, hopefully, with funding to phase 3 studies. And that's I think, really exciting because we have three drugs that potentially could be protective or disease-modifying for Lewy body diseases that would be in clinical trial. So I think that's exciting. The rest of the pipeline is farther behind. The Lewy body dementia pipeline doesn't look anything like the Alzheimer pipeline. For Alzheimer pipeline has 168 compounds with 190 trials. The Lewy body dementia pipeline has four drugs currently being tested. So big difference.

NANCY KEACH: And there's treatments that are for underlying cause. There are treatments for symptoms. So there's a lot of different categories here.

DR. JAMES GALVIN: Symptomatic treatments out there, yes.

NANCY KEACH: And I just want to mention for those of you that are looking for deeper information specifically about the drugs that are now approved to treat Alzheimer's disease, please refer back to the episode that we did recently on Leqembi and Kisunla. And there have been several episodes that look specifically about lifestyle interventions that have evidence to suggest that they are effective in slowing progression of

Alzheimer's specifically. So I am trying to stay today since we've recently covered these topics in depth a little more on the Parkinson's and Lewy body therapeutics and clinical trials because we have never talked about them here.

Peter in Portland, Oregon, asked, "Why do other types of dementia stop you from getting treatment with Kisunla?"

DR. JAMES GALVIN: So you have to have amyloid in order to be eligible for to be treated with these medications. So amyloid is present in Alzheimer's disease. We do know it's present in about 80% of people with Lewy body dementia. So that's why you mentioned this trial TRAILBLAZER-ALZ 7, which is going to test that. Most of the other dementias do not have amyloid. So frontotemporal degeneration is not amyloid disease. Vascular dementia can have some amyloid. But that cerebral vascular disease is a contraindication to using Kisunla or these other monoclonal antibodies. And those other rarer forms of dementia don't have amyloid. So if you don't have amyloid, you can't get Kisunla. And if you have a contraindication, like cerebrovascular disease, you can't get Kisunla. So that's why it's restricted to treating people with Alzheimer's disease at the present.

NANCY KEACH: Right, and some of the clinical trials of therapeutics for Alzheimer's originally were negative or failed. We don't like to say failed, but they were negative because, as it turned out, the people they were testing it on maybe didn't have that protein. They had a different protein. So now, the fact that you can't use, say, Kisunla if you don't have amyloid is actually a wonderful advance so that people are not getting treated with drugs that are not going to be meaningful for them or may even cause some harm.

DR. JAMES GALVIN: Yes.

NANCY KEACH: Amy asks in the chat-- and I love the question. Thank you, Amy-- how do we participate in Lewy body drug studies?

DR. JAMES GALVIN: So that's a great question. So without clinical trials, there will be no new medications. And without participants in clinical trials, there won't be a clinical trial. So there are several ways of finding out things. The broad common source is clinicaltrials.gov. That has all of the clinical trials performed in the United States, and many performed around the world. They're all registered there. So you just have to put in the disease of interest. You could click what state you're in. It'll tell you all the studies that are ongoing and actively recruiting for that.

NANCY KEACH: And I'll mention that on the BrightFocus website, we have also a

widget or a clinical trial finder that is a little easier to navigate than clinicaltrials.gov. But either of those will bring you to all the active trials if you put in Lewy body because it'll say, what are you looking for? Because it might say mild cognitive impairment, it might say Alzheimer's. It might say, memory problems. So put in Lewy body to participate in those. And I just had looked this up ahead of time for the TRAILBLAZER-7 because I think that just recently started recruiting that you can call 1-877- clinical trial Lilly, 1-877-285-4559. Or if you're interested in that specific one. There are 72 trial sites in the US, and I just happen to have note that one. And I know there are a few others, as you mentioned.

DR. JAMES GALVIN: I was going to say disease associations and foundations will also have websites. That's all I was going to say.

NANCY KEACH: Right. And Lewy Body Dementia Association is a great resource for these studies. I'm going to jump now to behavioral symptoms because there is so much interest pain, confusion. So Alyssa from Little Neck asked, "How do these types of dementias vary in terms of caregiving struggles?" And I'm going to say there are a lot of questions specifically about hallucinations. Amy writes, "My husband has auditory hallucinations all the time, and visual hallucinations only sometimes. The hallucinations make him angry and are often about me doing bad things. His behavior is hard to deal with. Is this an indication of Lewy body? Do you have suggestions about how to handle the accusations that I'm having affairs, locking him up, or doing other mean things."

DR. JAMES GALVIN: First, I'm very sorry to hear that your husband's experiencing that and that you have to go through that. So just like each patient's journey is different, each caregiver's journey is unique and special and different to that caregiver. And so the first thing I would say is if you're with your loved one, and that loved one is experiencing any behavioral symptoms, the first thing I would say is you, as the caregiver, need to make sure that you get support to help you cope with these things. So join a support group. Sign up with the disease associations, the National Caregiver Alliance, foundations. Find the support you need to help you navigate this very difficult path. So let me say that first.

Second thing is, not all behaviors need to be treated. Some behaviors, they occur. And as long as you can accept the fact that a behavior is occurring, if it's not causing a problem with patient care, with patient safety, or with your safety, the behavior may not need to be treated at all. If the behavior is causing a problem, the first thing to do is to learn about non-pharmacological approaches. So the simplest one is distract and redirect. So basically, you get the patient focused on something else. And sometimes that behavior will go away. You want to identify if there are any triggers for the behavior

and try to remove those triggers. So every time a person walks past a mirror, they think that there's someone in the apartment with them, then cover up the mirrors. So there are lots of non-pharmacological approaches and training programs to teach you how to do these non-pharmacological approaches.

If the behavior is not responding to a non-pharmacological approach and is affecting patient care, patient safety, or yours or someone else's safety, you need to speak with your health care provider. While there are not a lot of medicines approved, there are some medicines approved for treatment of different behavioral symptoms. There's medicines approved for treating agitation. There's medications that have been approved for the psychosis associated with Lewy body dementia. So is your loved one a candidate for these medications? And someone has to then monitor these medications to make sure that they're, one, effective and, two, are not having any side effects. So there are approaches, but the first thing is that you have to make sure you're taking care of yourself and that you have the support, because this is the beginning of the journey, not the end of the journey. And so there are lots of organizations and associations out there to help. So please take advantage of them.

NANCY KEACH: We did an entire episode on agitation, Alzheimer's agitation specifically. And I'm going to ask this again here because what does somebody do if they feel that they're in danger from their loved one or that the loved one is so combative or accusatory, violent that it's affecting their ability to live their life. What types of resources? Where do they begin?

DR. JAMES GALVIN: So again, you want to make sure that you're safe, that you have support and that you have someone that you can talk to. You want to discuss this with the patient's provider because there are now options available. There are medications that are approved to treat agitated and aggressive behaviors. Now, some of them don't work fast. Some of them take a while to work. So sometimes there are things that we do in the short term that are not the things I would want to do for long term.

And if there's a real threat, then think about emergency services so that sometimes temporary placement is necessary for someone who is out of control and can't be controlled behaviorally. That's not the first option you think of. But if you're not getting help that you need, that may be an option. So again, the first thing is, make sure that you have support that you're safe. Talk with the provider. There are medications available. And if necessary, then placement at least temporarily to some of those behaviors are better managed so that there are a number of approaches. But first thing, you always have to make sure that you're safe.

NANCY KEACH: And Lucy from Las Vegas is asking, "If a family sees firsthand the hallucinations and delusions and communicates this to a doctor, why do they dismiss what a family member will say about the matter?"

DR. JAMES GALVIN: I can only say you might want to speak to a different doctor. I don't know how else to put that right, because what you tell us is what you're observing, and hallucinations come and go. So the person may not hallucinate in front of me. But if someone says that the person is hallucinating, I take that very seriously. And then I start to address those questions, as I mentioned. What are they hallucinating? Is it interfering with their care, their safety, or someone else's safety?

And parenthetically, I'll just say, so if someone sees pretty butterflies, and it's not bothering them, they can see pretty butterflies. That's fine. I'm not going to do anything about that. If they're trying to climb out of the 10th story window to catch the pretty butterflies, I need to treat the pretty butterflies because it's affecting their safety. If someone's delusional in believing that you're having an affair when you're not, and they're being aggressive toward that, we may need to treat that delusion, right? So it's important for the physician to listen if you're not getting the advice or help that you need, That's what second opinions are for. That's what helplines are for. The Alzheimer's Association has a 24-hour helpline. The Lewy Body Dementia Association has a helpline. Use those resources, get the help you need, make sure you're safe, and then talk to a provider or a specialist that can help you.

NANCY KEACH: Yes, and Lucy, I think that doctors will do that when they don't know as much as Dr. Galvin here. And they don't know what to say. They will dismiss. And so I think that is exactly the right advice. Find a doctor who's more of a specialist in this area, if possible, or call one of the associations. And BrightFocus has a helpline as well. But all of these associations will help get you to a provider who's who understands these diseases better. And in defense of doctors, they are so overwhelmed. They all cannot be dementia specialists. We did a study once and found out that in medical school, typically, there are four to five hours of education on dementias. And I don't know. I've been doing this for almost 20 years, night and day, and I still can't keep up. So I know a primary care physician is in real struggle to try to keep up with what's happening. But it is so heartbreaking when people are told, oh, just go home, this is normal, or their concerns are dismissed, and it's so common. So just know that you're not alone and that you can find a doctor who is more educated about dementias and symptoms.

I wanted to ask, this is a little bit of a jump, but there are some questions about it in the chat. For Alzheimer's disease and early cognitive impairment of many kinds, I'm

a big believer in some of the lifestyle interventions that are getting proven out to be effective, and in particular music therapy and therapies with the arts. And so somebody is asking here about-- and I don't know as much about Lewy body. I have focused on Alzheimer's for all these years. And so do music and arts therapies seem to be effective interventions with these different types of dementias?

DR. JAMES GALVIN: Artful approaches to aging and dementia are increasingly being used. And they can be effective in the right situation. Obviously, it's not an acute treatment. So if someone's agitated and aggressive art's not going to necessarily be the treatment. But we found that people who are engaged in the arts tend to have fewer behavioral symptoms. They tend to have better quality of life. They tend to be more interactive with their environment. And so it tends to have lots of positive downstream effects. And the thing about the arts is there's lots of them. And so if someone doesn't want to finger-paint, that's fine. Maybe they want to listen to music. Maybe they want to do origami. Maybe they want to build LEGOs. They're all activities that are engaging.

And they can have a very, very powerful effect in downplaying overall behavioral symptoms, giving people things to do. Many people act out because they're bored. They're not doing the things they used to do, and they're bored. And so people act out when they're bored, when they're engaged, they tend to act out a little bit less. So there's lots of approaches that can be taken. And if someone doesn't like something, try something different. And you may find that works. We have an artful outreach program. We offer drum circles, sound baths, origami, neurotangle. So we do lots of these different programs. They're very effective.

NANCY KEACH: I wish you would leave Florida and come to California and do some of those for us. A couple of people have asked about cannabinoids, or CBD, or talked about it for treatment. What do you know about cannabinoids?

DR. JAMES GALVIN: Yeah, so there are lots of people that are taking these either for medicinal or for recreational purposes. Some people will swear that they're helping. Right now, we don't have a lot of evidence that they do help. A report that's now a couple of years old was put together by the National Academies of Science, Medicine, and Engineering. Looking at all of the available marijuana-related literature that was available at that time. And basically, it was hard to find a positive study for most things. It was good for if you have cancer, and you had no appetite, it was very effective. For closed-angle glaucoma, it was very effective. For a lot of other things, it was hard to demonstrate an effect, but there's a lot of interest in it.

There was just a presentation at the last Alzheimer's Association meeting of a clinical

trial using a very, very specific combination of CBD and THC. THC is the psychoactive component of marijuana. So very, very, very specific ratio component and had a very positive effect on behavior. So I think that that's very promising because that was really one of the first well-done studies that showed there could be a benefit, but it was a very specific mixture. And the take home message from that was that I can't-- the person speaking-- I can't recommend CBD products. I can't recommend marijuana because we didn't test that. We tested this very, very specific ratio of these two compounds. But it's exciting that it could offer new opportunities for treatment.

NANCY KEACH: That's wonderful. Mary from Chesapeake, Virginia asked, "What is a good method for communicating with a friend who has Lewy body dementia who lives 800 miles away? She struggles with texting." I think I want to ask this and stick this in here because isolation, it's not only a risk factor for dementias, but it is really a tremendous problem, especially in the US.

DR. JAMES GALVIN: Yeah, it's an accelerator. So people who are isolated with a cognitive problem are going to do worse than people who are socially engaged. I don't have a good answer for you because long-distance communication requires some technology, and patients with cognitive problems have difficulty using technology. So if your friend has a granddaughter, great-granddaughter, grand niece, little kids are really good with technology. And so there's lots of ways potentially of being able to engage. But it is a hard problem because many older adults with cognitive problems are just not good at using devices. And so it's going to be very hard for them, and they may not answer the phone. They sometimes look at the phone and don't know what to do with the phone. And so they don't answer the phone. But if you could set up like a regular time, like every Tuesday night at 6:30, Mrs. X's granddaughter can Teams you or Zoom you or FaceTime you or WhatsApp you, that would be a way that you'd be able to communicate. But you're going to have to pull another party. And I don't have a really good answer for you. I'm sorry.

NANCY KEACH: Fair enough. Before we go to the closing discussions, Dr. Galvin, how old is your grandmother?

DR. JAMES GALVIN: Grandmother's 105. She lives in a long-term care facility. She does have mild Alzheimer's disease. But she wins every bingo game. She is the bingo master. And she always has been and continues to be, and she can still play rummy and she beats everybody, including my mother and my aunt. So she has really good days where she's very sharp and is very engaged, and she has days where she's things are a little bit off, and she doesn't recognize everybody. But yeah, I mean, I think the running gag in our family, she's going to outlive us all. My grandfather died in his 60s with Lewy body

dementia. My father's currently living with Parkinson's disease and cognitive problems. So maternal grandfather and father, so not on the same side of the family. So that's the thing. It's sporadic. It just happens in different people. And so I feel for everybody who's asking these questions because I not only have it as a professional activity. For me, it's a personal battle.

NANCY KEACH: And I brought this up. And thank you for sharing about your I think it was your maternal grandfather. You've shared some amazing personal stories online. And I just want to say, most of the research scientists-- we talk about neurologists not diagnosing and doctors dismissing people. And the truth is that most of the people in the field, especially the research scientists that I are there from tremendous passion to help people because most of us have it in our families and so do a lot of the research scientists. So thank you, Dr. Galvin for the incredible passion that you show and spending your life working on these diseases.

I also want to mention to Peter, who asked about vascular dementia, we did give vascular dementia short shrift today. In May, we did an entire episode on stroke and vascular dementias with Dr. Jason Hinman from UCLA. And so I'd refer to you to that. But sorry, there's always so much to cover in these. And we're always so blessed to have the greatest experts in the field on that particular issue or dementia that I really wanted to go deep into Lewy body since we hadn't done it before.

And while I'm having this little conversation, I have a question for you all because this is our 45th episode. We've been doing this since April of 2023, and we're delighted we're coming up on 8 million views. And we just started a podcast, Let's Talk Alzheimer's, in June, which is actually this show repackaged. We take the conversation, and we do it for podcast.

But a lot of people have asked to share personal stories, and we have a database of people with personal stories and also a lot of celebrity connections. I mentioned Susan Schneider Williams and Lauren Miller Rogen. We're about to share some work from Andre Royo, who was in The Wire, about his mother and her journey with Alzheimer's. So my question to you is, would you be interested-- right now we focus only on the research. We are an organization that funds research globally. So we try to have programs that are specifically about new research, giving you information on the topics, and we will never stop doing that. But if we also did a podcast that brought on people with these very powerful stories, or even researchers telling their personal stories, would that be of interest to you? And please write yes in the chat if that would be interesting to you in addition to these stories that focus or these programs that specifically talk about research because we can do both. I just don't know if you all

feel like that's already being done. I can get those conversations anywhere, or-- OK, I'm seeing a lot of yeses. So thank you. Thank you. We try to humanize the research discussions because there is emotion under all of these conditions.

DR. JAMES GALVIN: I'll say yes too.

NANCY KEACH: You'll say yes too? OK, great, and we might have you on there. But Dr. Galvin, again, thank you so much for sharing your professional and personal work with us. I am going to say that our time today has come to a close eye. In addition to Dr. Galvin, I want to thank my wonderful colleagues at BrightFocus Foundation, Dr. Sharyn Rossi, who's been answering some of your questions, also our producers, Amanda Russell and Alexa Villarreal, the team M Square who are giving us this wonderful platform where I can actually see your faces, which I just love. And again, Dr. Galvin, thank you for your time today.

I mentioned that we've just launched the new podcast that is available anywhere you can look at podcasts. We've dropped six episodes so far. We will also have the 44 prior episodes, which have amazing information from the world's greatest researchers. So please find them at BrightFocus.org/zoomin I'm going to again call out a link to Susan Schneider Williams' "The terrorist inside my husband's brain," which was a wonderful essay. We also have produced this infographic that lists all of the FDA-approved therapeutics for Alzheimer's disease, symptomatic and disease-modifying. You can just go and get this off of our website or ask us to send it to you.

If this program is helpful to you, it would probably be helpful to people that you know. Please share the link with them, BrightFocus.org/ZoomIn. You can contact us with topics, suggestions, et cetera.

On August 20, we're going to be thrilled to have Dr. Zaldy Tan from Cedars-Sinai on, and he will be discussing reducing dementia risk, what the new research reveals. The World Health Organization just revised their guidance to list 14 modifiable risk factors, and he's going to talk about some research that he's doing. And then at the end of August, part of our clinical trials series, Gil Rabinovici will be joining us to talk about trontinemab, this new drug that has a unique brain shuttle mechanism. I won't try to describe it now, but there are several trials, either in progress or soon to be recruiting with trontinemab. So we're going to go deep in the weeds on the trials and the mechanisms of trontinemab.

So I'm just going to say, as I do at the end of all of these episodes, we are really grateful to you for participating, for staying on when I go over time, which I tend to do. Sorry about that. Thank you for participating. You're the reason that we're doing all this work

and very passionate about it. And I want to say, you're not alone. We're here for you. And remembering that life is very short. Tell everyone you love how much you love them. Give them a hug and keep them close to you. Enjoy them while you have them. Thanks again to everyone who's joined us. I look forward to seeing you again soon. Be well. And thanks. Thanks, Dr. Galvin. I'll be in touch with all the results. And again, really, really appreciate your time. Thank you.

DR. JAMES GALVIN: Thank you for having me.

Resources:

- Is it Alzheimer's Disease or Lewy body Dementia?
- Special Editorial "The terrorist inside my husband's brain"
- FDA-Approved Alzheimer's Therapies Infographic