## CURE Epilepsy Webinar The Effects of Exercise on Epilepsy Presenter: Dr. Halley Alexander (Transcript)

Laura Lubbers:	<u>00:00</u>	Welcome everyone to today's webinar. I'm Laura Lubbers and I'm the Chief Scientific Officer of CURE Epilepsy. I want to thank you for joining us today.
Laura Lubbers:	<u>00:09</u>	Today's webinar is entitled The Effects of Exercise on Epilepsy, and is intended for everyone, including people with epilepsy, caregivers, and physicians. Studies show that people with epilepsy are more sedentary than the general population. This is partially due to concerns about having a seizure while playing sports or exercising, and the fact that healthcare professionals have previously advised against physical activity. Many people with epilepsy, caregivers, and even some doctors are unaware of the research surrounding physical activity for those living with epilepsy. And unfortunately, studies have shown that up to 80% of people with epilepsy exhibit some form of cardiovascular disease and have a threefold increased risk of sudden cardiac death. These statistics actually suggest the need for more physical activity among those with epilepsy. A fact that is reinforced by recent research.
Laura Lubbers:	<u>01:04</u>	This webinar is part of CURE Epilepsy's 2022 Leaders in Research webinar series, where we highlight some of the critical research that's being done on epilepsy. Today's webinar, like all of our webinars, is being recorded for later viewing on the CURE Epilepsy website and you can also download transcripts of all of our webinars for reading.
Laura Lubbers:	<u>01:25</u>	For over 20 years, CURE Epilepsy has raised millions of dollars to fund epilepsy research that supports our mission, which is to find a cure for epilepsy by promoting and funding patient focused research. CURE Epilepsy provides grants that support novel research projects and that advance the search for cures and more effective treatments.
Laura Lubbers:	<u>01:45</u>	Today's webinar will explain the difference between exercise and physical activity, summarize the health issues faced by many people with epilepsy, and discuss who may benefit from physical activity. Viewers will also hear about the current consensus among medical professionals on the safety of different types of physical activity and exercise for people with epilepsy. Finally, viewers will learn practical tips for how to stay safe when engaging in physical activity.
Laura Lubbers:	<u>02:16</u>	Today's webinar will feature Dr. Halley Alexander. Dr. Alexander is a assistant professor of neurology at Wake Forest School of

		Medicine. She is board certified in the areas of epilepsy and clinical neurophysiology. Her research focuses on evaluation of the effects of physical activity in people with epilepsy on seizure control and epilepsy associated comorbidities. Dr. Alexander is working to develop physical activity programs that are accessible to those with epilepsy, taking into account the unique barriers to exercise that people with epilepsy may face.
Laura Lubbers:	<u>02:54</u>	Before Dr. Alexander begins, I'd like to encourage everyone to ask questions that we'll address during the Q&A portion of the webinar. You may submit your questions for Dr. Alexander any time during the presentation by typing them into the Q&A tab located on your Zoom panel, and then click send. We'll do our very best to get through as many of the questions as we can. We do want this webinar to be as interactive and informative as possible, however, to respect everyone's privacy, we ask that you make your questions general. So, with that, I'll turn it over to Dr. Alexander.
Dr. Halley Alexander:	<u>03:29</u>	All right, thank you very much. I'm excited to be here today to talk to everyone about the effects of exercise in people with epilepsy.
Dr. Halley Alexander:	<u>03:40</u>	Just seeing if I can get the slides working, there we go.
Dr. Halley Alexander:	<u>03:46</u>	Talking points, as Laura mentioned, we are just going to talk about the difference between what is exercise and what is physical activity, how people with epilepsy might benefit from physical activity, what are the different types of activities that are recommended in epilepsy, and then learn some practical tips on how people with epilepsy can safely engage in physical activity.
Dr. Halley Alexander:	<u>04:10</u>	So first, it's important that we define what we're talking about when we say physical activity and how exactly is that different than exercise. So physical activity is any bodily movement produced by skeletal muscle that requires energy expenditure. So that would include everything from walking from your car to your office, doing dishes, playing with your kids that's all physical activity. But exercise is a subset of physical activity, and that's when you are doing planned, structured, repetitive activities that are purposeful, in the sense that you are doing them for the sole reason of trying to improve some component of physical fitness. So, exercise, like I said, is a subset of physical activity and all physical activity does not necessarily mean exercise. And it's important that we distinguish between the two, but it's also important to note that physical activity in itself

is also important for general health. It does not always have to be exercise.

Dr. Halley Alexander:	<u>05:18</u>	So how much physical activity are we supposed to do? The CDC recommends that all people, not just those with epilepsy, all people should engage in moderate intensity aerobic activity for 150 minutes every week. So, for example, that would mean about 30 minutes a day, five days a week. Or if you look in the second column here, that could be vigorous intensity aerobic exercise, or aerobic activity such as jogging or running for 75 minutes a week. Or in column three, you of course can do some sort of equivalent combination of the two. And then also, they do recommend two or more days a week of muscle strengthening activity. So that's for everyone, including people with epilepsy. And of course, that's difficult for the general population to meet. It takes a lot of discipline and commitment, but it's also difficult for people with epilepsy.
Dr. Halley Alexander:	<u>06:21</u>	And the reason that we're talking about it today is that it's a problem that people with epilepsy are not as active as they need to be. And multiple studies have shown that people with epilepsy are less physically active than the general population and significantly less likely to be meeting these recommended physical activity guidelines. One study showed that about 56%, so a large majority of people with epilepsy do not meet these physical activity guidelines.
Dr. Halley Alexander:	<u>06:57</u>	And we know that it's important for everyone to engage in some forms of physical activity because it's good for their general health, but we actually think that it might be especially important for people with epilepsy to be engaging in physical activity because they have increased incidents of several diseases or disorders that should benefit from physical activity. So here are some examples. People with epilepsy have increased mortality and some of that could be due to the fact that they have increased prevalence of these various diseases; cerebrovascular disease, heart disease, high blood pressure, high cholesterol, diabetes, obesity, arthritis, et cetera. All of which we know can benefit from physical activity. Then of course they have increased rates of mood disorders such as depression and anxiety, increased prevalence of sleep disturbance and cognitive impairment. Again, which we know from studies in other populations can actually benefit from physical activity.
Dr. Halley Alexander:	<u>08:06</u>	So looking at that data a little bit more closely, we'll start looking at mood. So how might physical activity affect mood in people with epilepsy. And this has been studied in several

		different ways. And many observational studies have shown that people with epilepsy who have higher physical activity levels tend to have lower levels of depression. The graph that you're seeing on the left here is from a randomized controlled trial that was done in 2001, where they looked at the effects of exercise on this standard form called the Profile of Mood State. And the circles here are the group of people with epilepsy who engaged in exercise, compared to the squares, which is the people who did not exercise. So, you can see that in the group of epilepsy patients who underwent exercise, they had lower levels of tension, lower levels of depression, lower levels of anger, increased vigor or energy, and lower levels of confusion.
Dr. Halley Alexander:	<u>09:14</u>	And then, on the right here, I've listed several other studies that have shown that there has been improvement in depression scores in people with epilepsy, improvement in stress levels in people with epilepsy. And that's been in adults.
Dr. Halley Alexander:	<u>09:31</u>	And then, in children, they've shown that parents have rated improvement in behavioral and social problems and in mood related wellbeing in their kids after undergoing an exercise program.
Dr. Halley Alexander:	<u>09:44</u>	And in animal models, they've also shown that doing voluntary exercise has alleviated depression-like behavior in animal models of epilepsy who also exhibit depression.
Dr. Halley Alexander:	<u>10:04</u>	So then, looking at cognitive function, so here's another graph showing something similar. So, we have in red the people with epilepsy who had an exercise intervention. And in blue, the people with epilepsy who did not. And you can see that over time, the people who exercised showed improvements in their scores of verbal learning, so one aspect of cognition. And that same study showed that this improved performance actually was associated with changes that they could see on functional MRI imaging, changes in brain connectivity. So that's implying that the exercise is affecting the brain in some way that's related to these improvements in verbal learning.
Dr. Halley Alexander:	<u>10:48</u>	On the right, you see another graph. Again, a similar concept. In the pale pink here is the group of epilepsy patients who exercised compared to the group who did not. And you can see that they had significant improvement in their executive functioning. So that's things like thinking, planning, processing, with an exercise intervention. So those were both in adults.
Dr. Halley Alexander:	<u>11:13</u>	And then, again in children, there was a study in children who had what was called benign epilepsy with central temporal

		spikes. And they showed a significant improvement in their visual and auditory attention, as well as executive function after just five weeks of an exercise program.
Dr. Halley Alexander:	<u>11:33</u>	And then again, this is all supported by the animal models, which have shown improvement in cognitive tasks in the animal models of epilepsy after they undergo an exercise program.
Dr. Halley Alexander:	<u>11:46</u>	Looking now at sleep, so this hasn't gotten quite as much attention in the literature, but it is something that we are researching. And we know that problems with sleep are common in children and adults with epilepsy. So, they estimate that the prevalence could be as high as 50%. The graph here on the right I'm showing was a single study that looked at rates of insomnia in people with epilepsy. And you can see that more than half have at least a mild insomnia. And these sleep disturbances that are common in people with epilepsy could be due to a number of things. So it's possibly seizures could be occurring at night, medication side effects could be due in part to concurrent mood disorders, sleep apnea and other primary sleep disorders, and poor sleep hygiene.
Dr. Halley Alexander:	<u>12:40</u>	But this is important because in epilepsy sleep, we know, is a major trigger for breakthrough seizures. So, we really want people with epilepsy to be sleeping adequately. And also, the less you sleep, the worse cognitive deficits could become. And of course, the lack of sleep can affect mood. And poor sleep quality has been shown to be a significant predictor of lower quality of life in people with epilepsy.
Dr. Halley Alexander:	<u>13:08</u>	Now, as I mentioned, this hasn't been looked at as extensively in humans with epilepsy. And by that, I mean looking at specifically whether physical activity could improve sleep in people with epilepsy. But we do know, again from animal studies, they've showed that acute exercise in the animal model of temporal lobe epilepsy improves sleep consolidation. So, there is some data to suggest that would be true in humans with epilepsy. And of course, in humans without epilepsy, they've studied it pretty extensively, that increasing physical activity improves sleep.
Dr. Halley Alexander:	<u>13:47</u>	And then lastly, several studies have shown that physical activity in both adults and children with epilepsy results in improvement in overall quality of life. So regardless of its effects on any of the other comorbidities, we can say that people generally report improved quality of life with incorporating physical activity into their routines.

Dr. Halley Alexander:	<u>14:15</u>	So now I've given you a lot of information about why physical activity may benefit people with epilepsy. And we also know that people with epilepsy in general believe this. So, they report that they think that exercise increases their physical health, they believe that it decreases their stress levels, increases self- esteem, impacts their mood in a positive way, improves their quality of life, and even improves their seizures.
Dr. Halley Alexander:	<u>14:43</u>	So the question then is; why aren't they doing it more? Because I've shown you already on that first slide that they don't seem to be engaging as much as other people are. So, in looking at that, you have to take into account why doesn't anyone exercise when we all know it's good for us. And so, there's a lot of common barriers; lack of time, lack of motivation.
Dr. Halley Alexander:	<u>15:12</u>	And so, this graph on the right here is from a study that we did at our center, where we surveyed about 100 people with epilepsy and asked them, "What are your barriers to exercise?" And you can see that some of the responses are common to all of us. So, no time being one of the major responses. But then also, there are barriers that are unique to people with epilepsy. And so, right here, another commonly reported barrier is fear of having a seizure. And that's consistent with what other studies have shown, that the main barriers to sports and exercise are fear of the seizure occurring, fear of seizure related injuries, stigma, and incorrect advice from medical professionals. And so, these are the barriers that we really need to be working to address to get people with epilepsy more active.
Dr. Halley Alexander:	<u>16:10</u>	So then looking back, where has all this come from? So, as we've touched on a little bit, these are some outdated beliefs, where medical professionals did advise against physical activity for people with that epilepsy. So, looking here at 1968, the American Medical Association actually recommended restricting physical activity in people with epilepsy due to fear that it would induce a seizure activity or cause injury. And that really wasn't based on any science or any data that they had, it was just more of an assumption.
Dr. Halley Alexander:	<u>16:49</u>	So in the 1970s, people started challenging that. Saying, "There really isn't any medical literature to support this. We don't know for sure that people with epilepsy are at increased risk."
Dr. Halley Alexander:	<u>17:02</u>	And in 1974, the AMA then, their committee on medical aspects of sports said that all cases should be judged individually and participation in contact sports could be permitted if to do so is considered a major ameliorating factor in the patient's adjustment to school, associates, and the seizure disorder.

Dr. Halley Alexander:	<u>17:24</u>	And in 1984, we have a statement from the American Academy of Pediatrics Committee on Children with Handicaps and the Committee on Sports Medicine, and their position is that people with epilepsy should be allowed to play in most sports if their seizures are properly controlled and proper supervision was provided. So that does kind of suggest that if your seizures are not properly controlled, so if you're not seizure free, then maybe you shouldn't be participating in sports.
Dr. Halley Alexander:	17:54	So then, finally in 2016 we have the consensus statement from the ILAE. So, the International League Against Epilepsy got a group of experts together to really look at all the data that had come about since 1984. And together, they came up with, I don't want to say guidelines, it's not necessarily guidelines, but it's a consensus of experts on what they recommend for physical activity in people with epilepsy. And they state, it's one of the first sentences in the paper, that these prior attitudes limiting participation in people with epilepsy were largely due to fear, over protection, and ignorance. So, saying, "In the past, recommendations were made, but we didn't really have the data to support them. And it's not in the overall best interest of our patients to be restricting their physical activity." And they go on to say that people with epilepsy should engage in physical exercise programs and sports activities, certainly as long as they don't impose a significant risk of injury to themselves or to others.
Dr. Halley Alexander:	<u>19:11</u>	So I did want to specifically touch upon this question, because I know this is the big barrier here. So, what's the information that the league of experts based their consensus statement on? So, here's a slide just kind of summarizing a lot of that. And like I said, this is the big question; does exercise induce seizures? And the data that we have is The short answer is no. Many human studies have been done in people with epilepsy, where they've had them exercise at high intensities, so up to 60%, up to 80% of their maximal VO2 max. And none of them have showed that exercise increases the risk of seizures. And in fact, some studies have shown improvement in seizure frequency with exercise.
Dr. Halley Alexander:	<u>20:07</u>	There's also been studies that looked at whether exercise changed levels of the anti-seizure medications in the blood, because there was some concern that maybe exercise could alter the metabolism of those. And again, the findings were that there was no change in the anti-seizure medication levels.
Dr. Halley Alexander:	<u>20:27</u>	And then, on the right here, this is data in animals. So this is data from Dr. Arida, who's published the majority of animal data on exercise in the animal model of epilepsy. And so, he's

		looked at over 2000 hours of exercise in over 115 animals and only saw seven seizures, three of which occurred during exercise, and four after exercise. And again, these are animals that are having seizures all the time. So, by sheer coincidence, they are going to have some seizures during exercise. And they also showed that there were no seizures during the maximum oxygen uptake test, which is where they exercise the animals to exhaustion. So that's high intensity exercise.
Dr. Halley Alexander:	<u>21:17</u>	And then on the bottom here, I've shown a sample of a EEG because several studies have looked at the actual brainwaves by using EEG during and after exercise. And they've looked at it in adults, in children, in focal epilepsy, generalized epilepsy. And they've shown that exercise actually results in a reduction in epileptiform discharges and even seizures during the exercise itself.
Dr. Halley Alexander:	<u>21:55</u>	Sorry, just getting the slide going here. Whoops. Yeah, there we go.
Dr. Halley Alexander:	<u>22:03</u>	So that's the data that these decisions were based on by this consensus group of experts. And so, now I want to actually show you what that data is. So, these are the actual tables from the paper.
Dr. Halley Alexander:	<u>22:19</u>	And what they did was they grouped the different types of activities into group one, meaning they were deemed to have no significant additional risk to people with epilepsy. So, any risks were the same to the general population as they are to people with epilepsy. And that includes most of the things that you think about when you think of exercise or sports. So, football, baseball, basketball, tennis. Athletics would include track and field, running, jogging, walking. So that's all in group one.
Dr. Halley Alexander:	<u>22:55</u>	Group two are sports that they considered would be moderate risk to people with epilepsy, but did not give an increased risk to bystanders. So, these include a lot of aerial sports like gymnastics, pole vaulting, water sports, so swimming, water skiing, et cetera. And then, sports that include weapons. So, archery, fencing, shooting. So, these are less common sports. And right off the bat, you kind of have the inclination that of course these might have some increased risk, as you know we generally advise people with epilepsy to not swim alone and to avoid climbing heights, working on ladders, those sorts of things.

Dr. Halley Alexander:	23:45	And then, group three are the high risk sports for people with epilepsy and they also actually pose some risk to bystanders as well. So that includes things like motor sports, race car driving, or operating other heavy machinery, aviation, so flying an airplane. Of course, these things have increased risk to bystanders as well.
Dr. Halley Alexander:	<u>24:12</u>	So now that you kind of understand the three groupings, we can look at what the recommendations are for each group.
Dr. Halley Alexander:	<u>24:21</u>	I think the slide is coming. There we go.
Dr. Halley Alexander:	24:28	So the table's a little bit busy. I tried to make it easier to read. So right off the bat, you can kind of ignore the first two columns because these don't apply to people with epilepsy. These are other seizure disorders. So, we're looking kind of at the middle here. On this left we have a column of people who are seizure free. And on the right is the column of people whose epilepsy has resolved. So right down the line, you can see if you're seizure free, or your epilepsy has been considered to be resolved, then you're permitted to participate in any group of sports.
Dr. Halley Alexander:	<u>25:04</u>	So I really want to kind of look at the middle here. So, they've categorized it into people who only have seizures during sleep, people who only have seizures without impaired awareness. So that would be like a myoclonic seizure or a seizure aura. And then here, people who have seizures with impaired awareness. So that would include some of the older terms like complex partial seizure, generalized tonic-clonic seizure, grand mal seizure.
Dr. Halley Alexander:	<u>25:36</u>	But what I want to show is that these group one activities, the really common things that we think of; jogging, walking, running, football, all those kinds of more common sports, those are generally permitted across the board in people with epilepsy. The only caveats they've placed is if you have these seizures with impaired awareness or you're having your medications withdrawn, then you would want to heed the neurologist's discretion if you have a type of epilepsy where your seizures are precipitated by a specific activity. So, I want to talk about that for a second, because I know I just said all the data shows that exercise does not increase seizures.
Dr. Halley Alexander:	<u>26:22</u>	So there is some rare cases where certain activities could precipitate seizures in certain people. Those cases are rare, like I mentioned, but it could be anytime somebody goes bowling, could be something about the bowling itself, could be the lights

		in the bowling alley. Any time that activity comes up, that person has a seizure. So that's what they mean, that these specific instances do need to be considered. But outside of that, they're considered generally safe, these group one sports.
Dr. Halley Alexander:	<u>26:58</u>	Group two sports, where there was just a little bit of an increased risk to people with epilepsy, again, they are not barred. They are permitted at the neurologist's discretion. So that's something that you want to talk to your neurologist about, about your specific type of epilepsy, your type of seizures. And the recommendation should take all those things into account. And when they say with restrictions, they generally mean with appropriate supervision.
Dr. Halley Alexander:	<u>27:28</u>	And then the group three sports, you kind of want to think along the driving laws. So, if your neurologist told you that you shouldn't drive, then you also probably shouldn't be participating in the group three sports. So, motor sports and flying airplanes.
Dr. Halley Alexander:	<u>27:48</u>	So I hope that provided some clarity and not more confusion. But I just wanted to point out that a lot of things are permitted for a lot of people with epilepsy, even if you're having active seizures.
Dr. Halley Alexander:	<u>28:01</u>	So now that we have this data, I want to kind of go back to the original problem. So, people with epilepsy still are not as physically active, despite that that consensus statement came out in 2016. So, it's been six years. So, what's the problem? And it seems like the problem is that not everyone is aware of the updated beliefs of the updated research and data that we have. And so, it doesn't seem to have made it into everyone's practice. And so, that includes patients, caregivers, and medical providers don't all seem to be aware of this information that we've gathered over the past few years.
Dr. Halley Alexander:	<u>28:47</u>	So this, again, results from this study that we did at our center, where 40% of our patients actually reported that their neurologist had never talked to them about exercise. And we're at a level four epilepsy center.
Dr. Halley Alexander:	<u>29:04</u>	This statistics here on the bottom, this is from a very recent study across many, many neurologists in Latin America. And they showed that with surveying these neurologists, 60% of them were not aware of this 2016 consensus statement, the tables I just showed you. So, they didn't know it existed. And 35% of them reported having no information whatsoever about physical exercise in people with epilepsy. And 57% of them said

that they were still restricting exercise in their patients whose seizures weren't controlled. So, as you can see, it's still kind of a lingering, I don't want to say stigma, but these myths are lingering.

Dr. Halley Alexander: <u>30:02</u> There we go.

Dr. Halley Alexander: 30:04 So how do we overcome this? Well, obviously we need to bring more awareness to the issue, which is exactly what we're doing today with these webinars. So, we want to expand this education and bring it to patients, providers, caregivers, and the community. And we also need to increase resources. So, there might not be a lot of places that people know to go. Like, "Where do I find more information about this?" as a patient or the caregiver. There is some information on epilepsy.com, the Epilepsy Foundation website, but we want information to be a lot more widespread. And then, we need to continue doing research on the effects of physical activity in people with epilepsy. Dr. Halley Alexander: And then lastly, I just want to end with what I promised, to give 30:53 you some practical tips of how to exercise with epilepsy, how

could you safely engage in physical activity.

Dr. Halley Alexander: <u>31:06</u> So first, you need to consult your doctor. So, I mentioned, a lot of those things on that table is individualized recommendations from your neurologist after they take into account your specific type of epilepsy, your type of seizures, how frequent your seizures are occurring, what medications you're on, whether you're taking your medications, all of those things. So, you do need to talk to your neurologist first. And of course, anyone who's about to start an exercise program should talk to their doctor before starting exercise.

Dr. Halley Alexander: <u>31:40</u> And I've been saying exercise, I think somewhat interchangeably with physical activity. So, it doesn't have to be regimented, discrete exercise. You just want to be more active throughout your day. So that's why we recommend to start small. So with even five minutes or 10 minutes a day, will actually make a difference. So doing little things like taking the stairs, just trying to move around more throughout your day. You could set an alarm just to do even five pushups or sit ups. Or just trying to pick up your pace when you're out walking the dog, try to get your heart rate up. And it doesn't have to be a big long session. You could break it up and do little things throughout the day.

Dr. Halley Alexander: <u>32:28</u> You definitely want to listen to your body. You know your body best, you know your seizure triggers best, you know your auras

		best, and how you feel when you're about to have a seizure. So you want to listen to that and not necessarily push through.
Dr. Halley Alexander:	<u>32:46</u>	And then, I recommend keeping a log, especially if you're worried still that exercise might increase your seizures. Keep track of when you're exercising, what you're doing, and then also compare that with your seizure log that you should be keeping anyways. And then, that's something that you can take to your doctor, and they can see if there's any patterns emerging there.
Dr. Halley Alexander:	<u>33:09</u>	And then ultimately, you want to aim for 30 minutes or more of physical activity. And again, it doesn't have to be exercise, it just has to be activity.
Dr. Halley Alexander:	<u>33:20</u>	And then, I just want to say that of course you could have a seizure while you're exercising. So that's why we need to try to be as safe as possible. And it's not, again, not that we think that the exercise would cause a seizure, but you could have a seizure while you're at the mall or at school. And we need to be prepared for these situations. So, you do want to make sure that the people around you know what to do if you have a seizure. So, you could share your seizure response plan with them. For example, if you go to a gym or you want to go to the Y and exercise, it's not a bad idea to make sure that people there know that you have epilepsy and what they should do if you were to have a seizure.
Dr. Halley Alexander:	<u>34:01</u>	And then, if you do think that you feel that consistently every time you try to engage in physical activity that it does seem to be aggravating your seizures, then you definitely want to take that information to your neurologist and have them reassess with you whether maybe you need to be making some changes.
Dr. Halley Alexander:	<u>34:23</u>	And I think walking is a great way to start. It's low risk, low cost, accessible. And if you can get a walking buddy, that's great. Then there's somebody with you if you were to have a seizure, but that shouldn't necessarily limit you. So, I usually tell my patients that, "If you want to go for a walk, but you're afraid you might have a seizure while you're out, or your caregivers or family is afraid, there are a lot of tracking applications out there now that you can download onto your phone, where your family can actually see where you are. See if you're not moving anymore, and then they might know where to find you if you're not coming home when they thought you would."
Dr. Halley Alexander:	<u>35:11</u>	So just before we end, if you don't remember anything else about what I said, there's a couple takeaway points. So please

		remember that there's many benefits to increasing physical activity for people with epilepsy. We don't have any evidence suggesting that exercise increases seizures. And in fact, we have data suggesting that it could improve seizure control. And when deciding what activity is safe for you, how much, et cetera, that those decisions need to be made on an individual basis and in discussion with your neurologist. And again, it doesn't have to be exercise, just any physical activity is beneficial, and every little bit counts.
Dr. Halley Alexander:	<u>35:55</u>	So with that, I think we may have some questions.
Laura Lubbers:	<u>36:00</u>	Terrific. Thank you so much Dr. Alexander. That was very informative. So, we will now begin the Q&A portion of our webinar. We had some questions submitted in advance and I know that there are questions that are queued up. If there are more questions, please do submit them via the Q&A tab on your Zoom panel and click send.
Laura Lubbers:	<u>36:18</u>	So let's go to some of the initial questions that were submitted. First question is, "One of the most challenging obstacles to getting enough exercise and activity is the feeling of constantly being fatigued and a sense of being sedated from the anti- seizure medications. Is there anything that can be done to address this issue?"
Dr. Halley Alexander:	<u>36:41</u>	That's an excellent question. So, I'll say a couple different things. One reason why we think that physical activity could be good for people with epilepsy is because of these medication side effects. And there's been at least one study that I can think of off the top of my head that showed that people reported a reduction in their medication side effects after they started exercising. So my recommendation would be to try not to let it keep you from starting the physical activity. That's a lot easier said than done. But I think if you can make yourself just start somewhere, like I said, a few minutes a day, you should find that increasing your physical activity, even though it's going to be hard at first because of those side effects, will probably reduce the side effects that you're experiencing. And then therefore, it will kind of just get easier day after day.
Dr. Halley Alexander:	<u>37:44</u>	The other thing that I'll say is that it could be worth talking to your neurologist about your medications, because we don't want anyone to have to live with side effects. And we have over 25 medications for epilepsy now. So, it's possible that they may be willing to work with you to try adjusting medications and finding a regimen where maybe you don't feel so fatigued.

Laura Lubbers:	<u>38:14</u>	Very good. Great advice. Thank you.
Laura Lubbers:	<u>38:17</u>	Another question came in that relates to a very tragic event that happened very recently with regard to a surfer. This is a surfer who died potentially from seizure while surfing, and this is a very scary possibility.
Laura Lubbers:	<u>38:36</u>	The person who posed the question also enjoys surfing and has epilepsy. And generally, they feel better physically after surfing and believes that the additional ATP produced in the body might help with brain health. So, I want to get a perspective on that. What are the thoughts on ATP production from exercise? Will it help reduce seizures at all? Are there other things that the body produces during exercise that might help reduce the chances of seizures?
Dr. Halley Alexander:	<u>39:07</u>	That's a great question. And that's all kind of research that we don't have answers to right now, but they are being looked at. We do have data outside of epilepsy and some from other neurological diseases even, especially in the Alzheimer's realm, where they've looked at what is actually changing in the body when people exercise and how might that be benefiting brain health. So, there are some neurotransmitters that they've looked at.
Dr. Halley Alexander:	<u>39:46</u>	Something that comes up a lot is BDNF, which is brain-derived neurotrophic factor, which is thought to increase plasticity of the brain, so kind of improving the health of neurons. But specifically in epilepsy, it really hasn't been looked at. So, there's many theories about what could be happening in the brain, different levels of different hormones, and again, neurotransmitters. And it's probably some combination of all of those things that's happening, but we don't have all the answers to that right now.
Laura Lubbers:	<u>40:26</u>	Okay, thank you. More research, critical, yes.
Laura Lubbers:	<u>40:31</u>	Here's a question about weightlifting, which was included in the moderate risk category, but the CDC recommends including strength training two times per week. Can you clarify or share your opinion on this?
Dr. Halley Alexander:	<u>40:45</u>	Another good point. So, it is definitely recommended to do some weight resistance type exercise. But of course, that is slightly increased risk in people with epilepsy because of the fact that if you're lifting a 30-pound weight, or lifting it over your head, if you are to have a seizure, there's a more

significant risk of injury there compared to just walking or running.

Dr. Halley Alexander: <u>41:16</u> And so, as far as I know, there aren't any official guidelines or recommendations about that. But one thing that I think would be safer if you want to incorporate resistance training and you're having frequent seizures is possibly using resistance bands, because you can get the same idea, same kind of effect on the muscles as weight lifting, but it's a little bit safer in that you're not lifting a weight that could drop, you're just working with the resistance of the band.

- Dr. Halley Alexander: <u>41:51</u> Sorry, my computer just made a noise now.
- Dr. Halley Alexander: <u>41:53</u> I'm not a personal trainer, so I can't suggest any specific exercises with the bands. And of course, I don't know the context of this person's specific epilepsy, but that might be somewhere to start.
- Laura Lubbers: <u>42:07</u> That's a great idea, great consideration.
- Laura Lubbers: 42:11 There's a couple of questions that have come in that sort of relate to the level of exertion. So, should someone try to target a specific level of exertion or increase in heart rate? And along the same lines, can you speak to the idea of too much exercise? So, in this person's case, they've always run marathons, and have become afraid of going too hard and toned it down to half marathons as a compromise, which I still think is amazing. So again, what level of exertion is reasonable?
- Dr. Halley Alexander: <u>42:52</u> Another good question and congratulations to that person for being so active. It's very impressive. And afraid the answer is that there is no one level necessarily. Exercise is one of those things that the more you do it, you kind of buildup gradually. And then, the more that you're able to do. So, for somebody who's training to do a marathon, for them to go actually run the marathon doesn't quite take the same amount of exertion and toll on the body as it would for somebody who hasn't been training to go run the marathon. That could actually be disastrous for that person. So, there's not necessarily a level of exertion that is appropriate for everyone or everyone with epilepsy.
- Dr. Halley Alexander: <u>43:46</u> I'm trying to think of the best way to answer the question. I think, again, it has to be individualized. But for that person, listening to their body is probably a good way to start. If they're a marathon runner, they're probably familiar with the feeling of

a good type of hard workout and a bad type of hard workout, where hard feels too hard.

Dr. Halley Alexander:	<u>44:13</u>	So again, I can't give a definite answer to them, but I think that working with their neurologist and just listening to their body. But I will say, running and that type of high intensity exercise High intensity, so that means the intensity of the exercise in that moment was not shown to increase seizures. But when we're talking about marathon running, we're actually talking about low intensity exercise over a longer period of time. And that, I don't think has been looked at in people with epilepsy and probably won't be. We won't be making them run long duration to test that, so we don't have the data there.
Laura Lubbers:	<u>45:04</u>	Okay, thank you. So, are there any limitations on exercise when you have a VNS?
Dr. Halley Alexander:	<u>45:12</u>	That's another good question. And again, it's probably not going to be the same for everyone. In general, no, having a VNS wouldn't necessarily mean that you have to limit your exercise.
Dr. Halley Alexander:	<u>45:27</u>	The reason I say that though is that some of the newer VNSs, they can be set to go off if they detect increased heart rate. The reason for that is that a lot of seizures present with increased heart rate or a fair amount of them do, so the idea is that the device can actually detect that and then go ahead and give a stimulation to help abort that seizure. So of course when you exercise, your heart rate will go up. So, in those cases, again, it still wouldn't necessarily mean that you couldn't exercise, but you might want to be aware of that and be prepared for the idea that your device might go off a lot more.
Dr. Halley Alexander:	<u>46:11</u>	And if you're somebody who wants to engage in exercise regularly, depending on your seizures and your type of epilepsy, it might be something that your neurologist could adjust. They might be willing to adjust it so that it doesn't go off every time your heart rate increases a little bit.
Laura Lubbers:	<u>46:31</u>	Okay. Great. So, to some of the data that were presented, on the mood graph, why didn't exercise or activity decrease fatigue in relationship to non-exercisers? Both groups scored the same regardless of activity.
Dr. Halley Alexander:	<u>46:50</u>	Good question. And I don't know the answer to that, but I can offer a few points of speculation. So, it's possible that the group that was exercising I believe in that study it was either six weeks or 12 weeks. But when you first start an exercise

		regimen, you might actually be a little bit more tired because your body is working harder to adapt, which in the end is good, but in the short term could cause a little bit more fatigue. So it could be partly due to that.
Dr. Halley Alexander:	<u>47:30</u>	Could be, again, like somebody has already mentioned, that sometimes the seizure medications are contributing to some kind of fatigue or sleepiness. And so, it might be that in that study, the exercise group, despite reporting that they had more vigor, we saw that component had gone up, that maybe that wasn't enough to overcome That their medications were still making them feel a little bit fatigued. And I don't know how those two terms are perceived differently, vigor and fatigue.
Dr. Halley Alexander:	<u>48:09</u>	So again, I'm speculating on that, but I think it could be a lot of different variables. But we do have data from other studies and from that study, showing the vigor, where people have perceived that their energy levels are increasing. And so, I didn't show those graphs, but when we look at the quality of life scales and epilepsy, they have subdomains. So, a lot of them will look at physical function or energy level as a subdomain of the quality of life scores. And so, with exercise, in a couple of studies, people have reported improvement in the energy or the physical function domain of those subscores. So again, I can't explain that one study, but I do think in general people have been reporting feeling improvement in their energy with exercise.
Laura Lubbers:	<u>49:04</u>	Great. So, there are a number of questions that relate to various programs, styles of exercise, and I'm not sure that we can get through them all, but one sort of broad question is; is there a difference between physical activity indoors versus outdoors?
Dr. Halley Alexander:	<u>49:22</u>	That's a good question. I guess, it depends on what you're looking at, a difference in what exactly? But being outdoors has been shown to improve mood, even if you're not exercising. Being outdoors in the sunshine and the fresh air, that does seem to do a lot of good for a lot of people. So, I would say if the weather's okay and you're able to and you have the choice between the two, then going outdoors probably would have more benefits for you health wise.
Dr. Halley Alexander:	<u>49:59</u>	However, if we're talking about a dangerous outdoor situation, maybe it's not safe to walk in that neighborhood, or the weather's bad, or being at home and doing a stationary bike means you can have family members nearby who could help you if you were to have a seizure, whereas if going outdoors, your only option is to ride the bicycle, which that was a group

		two sport because you're out in traffic and everything, then looking at the difference between those two, it certainly would be safer to do the stationary bike inside. So probably depends on what you're trying to see a difference in, but there are differences between the two. But then, at the end of the day, physical activity is physical activity. So whichever way you can safely get it would be what I would recommend doing.
Laura Lubbers:	<u>50:52</u>	That's great. That's helpful. And just want to be clear that while some of the data focused on mesial temporal lobe epilepsy, this is broad advice for anyone with epilepsy, it's not just restricted to mesial temporal lobe, correct?
Dr. Halley Alexander:	<u>51:07</u>	Yes. Thank you for clarifying that. So, most of the studies looked at adults and kids, focal types of epilepsy, general type of epilepsy, some specific syndrome. So, it's broad advice for all epilepsy.
Laura Lubbers:	<u>51:22</u>	Okay. Great. So, there are still questions here. I'm not sure, again, that we will get through them all. People have asked if we'll make these slides available, and indeed the slides and the webinar itself will be made available on our website. Just give us a couple of days and we will get them up there for people to reference, again.
Laura Lubbers:	<u>51:44</u>	I will try to sneak in another question. And again, a great researchy question. "Are there any mitochondrial effects from exercises that could be a part of the benefits to epileptics from exercise?"
Dr. Halley Alexander:	<u>51:57</u>	Oh, very good question.
Laura Lubbers:	<u>51:59</u>	Yeah.
Dr. Halley Alexander:	<u>51:59</u>	Yes is the short answer. They've looked at the mitochondrial effects of exercise in humans and a lot of other disease in the general population, in other neurological diseases. Again, as far as I know, we don't have published data on that in people with epilepsy. But most likely, any of that, that's affecting brain health is probably going to be beneficial for people with epilepsy.
Dr. Halley Alexander:	<u>52:36</u>	The reason why we still need to specifically look at it in the epilepsy population, and we can't just assume, "Oh, it's good for brain health in Alzheimer's, it's probably good for epilepsy," is that epilepsy is somewhat unique than other neurological diseases, in that it's increased brain activity, increased signaling.

		And so, some of these neurotransmitters and things that might be more activating in the brain, which might help dementia or memory loss, we don't really know necessarily the effect it would have in epilepsy.
Dr. Halley Alexander:	<u>53:14</u>	So for example with BDNF, that increases synaptic plasticity and neurogenesis, but that's not always beneficial in people with epilepsy. So, if you have new neuronal connections being made, it's possible that kind of aberrant sprouting could actually be part of what could be related to the seizures themselves. So, we don't know any of that, but that's why we need to look at it in epilepsy, even though we've looked at it in other populations. And right now, we don't have those answers.
Laura Lubbers:	<u>53:59</u>	Great topics to continue to study to really parse this out. So, thank you so much.
Laura Lubbers:	<u>54:04</u>	So I think we will wrap it up here with the questions.
Laura Lubbers:	<u>54:08</u>	This concludes our webinar about exercise and epilepsy. I want to thank Dr. Alexander for your very engaging presentation. You're very much on the cutting edge of this and definitely needs to have additional study.
Laura Lubbers:	<u>54:20</u>	As always, I would love to thank our audience for great questions. You always amaze us with the depth of knowledge that you have and the questions that you have. If you have additional questions about the topic or wish to learn about any of CURE Epilepsy's research programs or webinars, please visit our website or email us at research@cureepilepsy.org. We will look at the remaining questions and see if we can develop some responses to them, and post those alongside the webinar when it is available on our website.
Laura Lubbers:	<u>54:49</u>	Finally, be sure to register for our next webinar, taking place in just a couple of weeks, on October 6th at 2:00 PM Eastern Time. This webinar will feature Dr. Jim Wheless, who will be speaking on advanced imaging in epilepsy and how technologies like MEG can assist with epilepsy surgery.
Laura Lubbers:	<u>55:09</u>	So I want to thank you all, again. And be well. Enjoy your exercising. It's a great time of year to be out there.