VNS: A Small Device Making a Big Difference Transcript

Kelly Cervantes:	00:00	Hi. I'm Kelly Cervantes, and this is *Seizing Life*, a weekly podcast produced by Citizens United for Research in Epilepsy, CURE.
Kelly Cervantes:	00:18	Today, Dr. Takijah Heard joins us from the North Shore Neurological Institute. She is the Division Head of Pediatric Neurology in Epilepsy where she treats a wide range of neurological conditions and specializes in epilepsy. In this episode, Dr. Heard shares how she uses the Vagal Nerve Stimulator, more commonly known as VNS. Dr. Heard, thank you so much for coming to chat with us today.
Dr. Takijah Heard:	00:40	Thank you for having me. I appreciate it.
Kelly Cervantes:	00:42	So, tell us a little bit about yourself. We got a little bit of your bio from that intro, but what made you decide to go into epilepsy?
Dr. Takijah Heard:	00:49	Going into medicine was something that I always thought about ever since I was young. My mom was sick growing up, and I saw how doctors have influenced our life. Whenever it made my mom feel better, the whole house felt better. I ended up being born here in Chicago, grew up in Texas, but came back to medical school at the University of Chicago. Between your first and second year of medical school, you have to do a research project. I felt like I had seen other things, but I had never seen a seizure and, whenever I got into my clinicals, which is in the third and fourth year, I wanted to make sure that I had seen a seizure.
Dr. Takijah Heard:	01:18	I did my research in epilepsy. It was in a lab with Dr. Marcuccilli. He happened to be my role model and the whole reason that I happened to be an epileptologist.
Kelly Cervantes:	01:26	We're a little partial to him in our family as well. He's my daughter's doctor. So, you're here to talk to us today about vagal nerve stimulators, the VNS therapy as a treatment for seizures. Can you explain the device to us and how it works?
Dr. Takijah Heard:	01:44	A vagal nerve stimulator happens to be a non-invasive procedure that can be done as an outpatient. It's a non-open brain surgery. It happens to have a coil that wraps around the vagus nerve, and there is a generator that is placed on the left side, maybe a couple of inches below the clavicle.

VNS: A Small Device Making a Big Difference Transcript

Kelly Cervantes:	02:02	You brought some of them here today. The device goes just underneath the skin, and then there are wires that come up and connect to the vagus nerve.
Dr. Takijah Heard:	02:17	Which happens to be in the neck.
Kelly Cervantes:	02:18	Why does it work?
Dr. Takijah Heard:	02:21	It ends up targeting the vagus nerves. The vagus nerves then connect to the brain and send amounts of energy that happen to be treatment amounts of energy to combat the seizure which the addition [inaudible 00:02:32] amount of energy to stop the seizures.
Kelly Cervantes:	02:36	How does it know when to work?
Dr. Takijah Heard:	02:39	It has great configurations in which it has a time frame in which it comes on, and then it has a time frame at which it gives the amount of energy. It could be 30 seconds; it could be up to a minute. Then we increase the amount of energy in milliamps until we get to a therapeutic amount, which is usually about 1.5 milliamps. That's when we start to notice that, as it cycles every five minutes, the seizure frequency will start to go down.
Kelly Cervantes:	03:06	I see. It is triggering the vagus nerve at whatever, every five minutes, or I'm sure at whatever you set that to be?
Dr. Takijah Heard:	03:16	Yep.
Kelly Cervantes:	03:17	Now, is it the kind of thing where, if someone feels a seizure coming on, they can trigger it to try and stop the seizure?
Dr. Takijah Heard:	03:25	Great question. They have a device called a magnet. It looks very similar to an Apple Watch. It's a large device that you can put on like an Apple Watch or wear it around your neck.
Kelly Cervantes:	03:35	Okay.
Dr. Takijah Heard:	03:35	You can trigger it by swiping it. I usually will put a W across the actual stimulator that activates it, sending an extra jolt of energy that's usually about .5 milliamps larger than the normal routine amount.

VNS: A Small Device Making a Big Difference Transcript

Kelly Cervantes:	03:49	Okay. Then how in the world did they figure out that this worked? Do you have any idea?
Dr. Takijah Heard:	03:55	No, not really, but we definitely noticed that the vagus nerve is one of the cranial nerves. This is one of the ones that happens to come out of the brain that we have easy access to. Is there a way in which we can get to the brain without it actually being an open-brain surgery?
Kelly Cervantes:	04:09	This device isn't in the brain, but, correct me if I'm wrong, I believe I've seen similar devices that can be placed on the brain? What is the difference between those two?
Dr. Takijah Heard:	04:20	The other device that can be placed in the brain that you leave and live with is something called Neuro Pace.
Kelly Cervantes:	04:26	Okay.
Dr. Takijah Heard:	04:26	It's a responsive device that you actually place in the brain. It's a brain surgery that lies within the skull itself.
Kelly Cervantes:	04:33	Two completely different devices?
Dr. Takijah Heard:	04:35	Correct.
Kelly Cervantes:	04:36	How is the VNS powered?
Dr. Takijah Heard:	04:39	It has a battery. The battery life can last anywhere from 5 to 10 years. 7 to 8 years is usually the battery life for most. Obviously, it could be shorter if we're doing the cycling much more frequently than 5 minutes. Then it could last up to 10 years.
Kelly Cervantes:	04:55	What happens when the battery runs out, because this is under your skin? It's not like the remote control where you can just pop new batteries in. This is a little more invasive.
Dr. Takijah Heard:	05:04	Well, not so much. The vagal nerve stimulator generator is going to be under the skin. They make a small incision where it's at. They place in a pocket, remove the generator from out of that pocket, and slide in a new generator. Again, it's a daytime procedure, so it's not anything you have to be in the hospital

		for. You get it done, you put in a new battery, and then you get to go home.
Kelly Cervantes:	05:24	Wow. How long does that procedure take? Both that initial procedure and then switching the generator out?
Dr. Takijah Heard:	05:34	It usually is a daytime procedure, only a couple of hours. You'll leave the hospital at that time, and then you'll return to see an epileptologist like myself, who will turn it on and get you up to the appropriate therapeutic dose of the energy every two weeks.
Kelly Cervantes:	05:49	How long typically does that process take, to get from the device is placed to the therapeutic, because I know with prescription drugs it can take weeks or months to get up to a fully therapeutic level. What is that process like with this device?
Dr. Takijah Heard:	06:13	You get the surgery. You leave. Two weeks later, you come to the office, and we'll give you a sub-therapeutic dose, but a dose that allows your body to get used to this new energy that's going to happen every five minutes. It should take about four to six weeks before you're at a therapeutic dose. Obviously, it could take a little bit longer if you have any side effects. Some of the side effects include hoarseness of your voice because it's not far from the nerve that deals with the voice. Another is a cough. Some people complain of shortness of breath, and sometimes people will feel like a humming or a change in the character of their voice.
Kelly Cervantes:	06:49	My next question was going to be about the side effects because I hear you saying the word dose in the exact same way that we would talk about a pharmaceutical med.
Dr. Takijah Heard:	06:57	Exactly.
Kelly Cervantes:	06:58	We all know that the pharmaceutical meds come with their fun array of side effects. Are there any other more severe side effects besides a scratchy voice and a cough? Can it get to the point where it's so uncomfortable that someone might have it removed? What have you seen in your experience?

VNS: A Small Device Making a Big Difference Transcript

Dr. Takijah Heard:	07:19	I do not see that often somebody actually having it removed. Some people will find the hoarseness to be too much for them, or the cough or the tickle in their throat to be a little bit annoying. Usually, we'll go back down on the dose. I allow them to get used to that, and then try to go up again.
Kelly Cervantes:	07:35	Who is a good candidate to try the VNS therapy?
Dr. Takijah Heard:	07:39	The great thing is that it has been FDA-approved for kids who are four years of age and older. It's happily done for kids who have intractable epilepsy. Kids who have already been on a couple of medications are usually better equipped to be started on the VNS. It's something that you add to their medical treatment, and, often, you'll start to notice a decrease in their seizure frequency after several months.
Kelly Cervantes:	08:04	You mentioned children, but this can be used in adults as well?
Dr. Takijah Heard:	08:07	Definitely. It just starts off in children and always goes all the way up to adults.
Brandon:	08:12	Hi, this is Brandon from Citizens United for Research in Epilepsy, CURE. Do you want to know about new discoveries in epilepsy research? Read the latest research insights at cureepilepsy.org. Now back to this episode of seizing life.
Kelly Cervantes:	08:24	Have there been any research studies? Are there certain types of seizures that it does a better job of controlling, or is it just a blanket treatment for all seizures?
Dr. Takijah Heard:	08:34	It is a blanket treatment for most seizures. Often times, we'll use it for focal seizures, as well as generalized seizures. With the focal seizures, sometimes we try to use the actual receptive surgery, the actual invasive brain surgery to try to remove that defective area of the brain to see if that truly can be the cure for that person's epilepsy.
Kelly Cervantes:	08:53	You mentioned that it is FDA-approved for patients four years and older. Has it been used in younger patients?
Dr. Takijah Heard:	09:01	It's definitely been used in younger patients. Kids who happen to have very intractable epilepsy, we do try to put the generator in. Often times, it's dependent upon their size, as well as the

		amount of subcutaneous tissue they have in the area in which the generator would sit.
Kelly Cervantes:	09:16	What does that tissue mean?
Dr. Takijah Heard:	09:20	The tissue that happens to be right below the skin. They need to be fat enough to where we can find a pocket.
Kelly Cervantes:	09:26	Those chunky babies. Those ones.
Dr. Takijah Heard:	09:28	Those are the ones we like.
Kelly Cervantes:	09:31	It works well with those. You brought a couple devices with you today. Apologies for those listening in that you're not able to see these, but I would say one is slightly bigger than a silver dollar and …
Dr. Takijah Heard:	09:47	Maybe as thick as two or three.
Kelly Cervantes:	09:48	… thick as two or three silver dollars. Would this one be, because I can't imagine something this large being placed in my daughter. She's three years old, and it would just take up such a large portion. You did bring a smaller version which is more of an oval shape, probably about half the size of the other one, but the same thickness. Would this be more of a pediatric size?
Dr. Takijah Heard:	10:12	Both of them happen to be pediatric size. This happens to be the older model. The smaller one happens to be the newer model. They have features that make them different, but, for the most part, because the newer model happens to be smaller and has many more features, that's the model that will be in most people moving forward.
Kelly Cervantes:	10:29	Got it. What are the features that make them different?
Dr. Takijah Heard:	10:36	We have aspire which is the model 106, which has the ability to monitor heart rate. As you know, whenever many people have seizures, their heart rate goes up.
Kelly Cervantes:	10:48	That happens with my daughter.

VNS: A Small Device Making a Big Difference Transcript

Dr. Takijah Heard:	10:50	What we end up doing is calibrating the normal heart rate for the person, and then identifying the 40%, 30%, or 20% increase in the heart rate, and then this will automatically go off.
Kelly Cervantes:	11:02	Oh.
Dr. Takijah Heard:	11:03	That's called the auto-stem feature.
Kelly Cervantes:	11:04	Wow. Okay.
Dr. Takijah Heard:	11:06	Sometimes that will capture some of the seizures before they actually happen.
Kelly Cervantes:	11:09	Okay.
Dr. Takijah Heard:	11:10	As soon as the heart rate goes up, it will send a treatment dose of energy, thereby stopping some of the seizures. It already will have the regulated routine amount that comes out every five minutes. Then you have the opportunity to swipe with your magnet, which gives many caretakers a lot of autonomy to stop the seizures whenever they have it.
Kelly Cervantes:	11:29	Okay. That's amazing to think because, some people have auras, or they can feel that seizure coming on or the very beginning stages of it, and they can communicate that, assuming they're verbal. But for children whose seizures have made them nonverbal, like my daughter, there's no way that she can tell me she feels something coming on. We have her constantly connected to a pulse oximeter which monitors her heart rate so we can look at that and see if her heart rate starts to go up. Everyone goes on alert to keep an eye out for when that seizure is going to happen. That would be a time where we could swipe?
Dr. Takijah Heard:	12:13	Right. Or it would capture it itself, and you wouldn't actually have to do anything. You can just change the percentage of the heart rate for it's 40%, 20%, or 10% increase, and then it would automatically give that extra delivery of energy at that time.
Kelly Cervantes:	12:28	Okay. What are some of the other really cool ... I had no idea they had all these other cool features. What else should we know about them?

VNS: A Small Device Making a Big Difference Transcript

Dr. Takijah Heard:	12:36	The SenTiva which is the more recent one, happens to have AM and PM dosing. Sometimes kids will have more seizures during the day and sometimes they'll have more seizures whenever they're sleeping at night. It would allow you to get a different dose of energy during the AM hours versus the PM hours, depending on when the frequency of their seizures may be. Sometimes you have something called frontal lobe nocturnal epilepsy, which happens nocturnally, at night. Then, you can give additional doses of energy at night. This is obviously the time at which they're less active. Some of the side effects like hoarseness and cough obviously will not be as bothersome to them because they're sleeping.
Dr. Takijah Heard:	13:13	Then the new SenTiva model also has the ability to detect if the patient is prone to seizures whenever they're sleeping. As you know, sometimes the prone position is the cause of sudden unexplained death. It gives us a general idea when they happen to be prone, and then that can turn into a way in which we can prevent the death of these epilepsy patients.
Kelly Cervantes:	13:36	Amazing. You talk about these different settings. How do you adjust these settings if it's inside the body? I mean, I'm looking at these. They're smooth. There's no buttons or dials on these. So how are you adjusting?
Dr. Takijah Heard:	13:50	Just like somebody who may have a pacemaker, you can feel the pacemaker. You can feel these just below the skin. There's a wand that we use which activates the generator, and there we can make setting changes. There is nothing that you feel. There are not any piercings or punctures to the skin. We just put it over the device itself.
Kelly Cervantes:	14:11	What have you seen as the success rate for using this? I imagine that it varies, but have people achieved seizure freedom using the VNS? Are there some people who it just doesn't work for at all? What can someone expect going into this?
Dr. Takijah Heard:	14:31	You could expect a reduction in your seizures with the VNS. You can expect that reduction to happen six months, a year, or two years down the line. The longer the device is in, you start to see continued improvement in the reduction of your seizures. Furthermore, as your seizures are reduced, you'll find that you'll be able to reduce your oral medications as well. It gives you a

		lot more independence. Just because you, as the patient who happens to have epilepsy, know that you not only have the generator giving you that jolt of energy every five minutes, but you also have the auto-detection and, for other caretakers who are around you, they have the autonomy to actually stop the seizure if you happen to have one.
Kelly Cervantes:	15:18	But you have to be patient. Because you're talking six months to two years once it's placed for you to see that difference in seizure activity. That can be a long time to wait to see a difference. It's interesting to me to wonder if they know why that is? Why it can take so long to see that reduction in seizures?
Dr. Takijah Heard:	15:41	The thought process is mainly built on the fact that you are changing the energy level, and you're trying to auto-modulate the brain waves in a way in which the new jolts of energy reduce the abnormal amount of energy that causes these seizures.
Kelly Cervantes:	15:55	At what point over the course of a patient's treatment plan would you sit down with them and recommend this piece of equipment?
Dr. Takijah Heard:	16:06	Often times, I'll recommend it for kids who are having very long seizures. Seizures that happen to be much more clinical and seizures that happen to be intractable. Meaning they've already tried two or more medications and still are having very frequent seizures.
Kelly Cervantes:	16:19	Has anyone found a difference in the efficacy for the cause of the person's seizures? For example, whether it is a genetic cause, whether it is a brain malformation, or it is post-traumatic cause of the epilepsy?
Dr. Takijah Heard:	16:37	No, it doesn't fully matter. The true cause of the epilepsy could be genetic, it could be post-traumatic, or it could be due to a brain malformation. The main thing is just trying to get an additional jolt of energy through the vagus nerve to try to see if they can combat the seizures that may be happening.

VNS: A Small Device Making a Big Difference Transcript

Kelly Cervantes:	16:54	It really seems to me that this device can help such a large swatch of the epilepsy population. Why is it not used more frequently?
Dr. Takijah Heard:	17:06	I think its sort of the personality of the patient and the personality of the caretaker. Sometimes, they don't want to go through a surgery and prefer to continue with medication. Sometimes, the actual placement of the device may be too much for their body habitus, or they may not have enough fat tissue to stick it there. Then, if there's a little bit of hesitation there, we wait and reintroduce it a little bit later.
Kelly Cervantes:	17:31	Dr. Heard, thank you so much for coming and chatting with us and teaching us all things VNS. I just know I learned so much today about this device, and I thought I was pretty educated on it. So, we really do appreciate that. As always, I love to take a moment just to thank all our pediatric epileptologists out there. We love what you do and keep doing it.
Dr. Takijah Heard:	17:54	Thank you. I appreciate being here.
Kelly Cervantes:	17:59	Thank you again Dr. Heard for explaining more about how the VNS works. This leading-edge device is a great tool helping many patients in the fight against epilepsy. Unfortunately, VNS does not work on everyone, which is why we need more than one approach to help treat epilepsy. To help with that mission, we ask you to donate to CURE to fund more patient focused research. Visit seizinglife.org/donate. No gift is too small. We appreciate your generosity.
Disclaimer:	18:34	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained herein is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions in need. CURE strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.