Epilepsy and Seizure Management Training Video Transcript

Welcome to today's Epilepsy and Seizure Management training. My name is Stacy Haitsuka.

I work here at the Developmental Disabilities Division training office. My office is located here on Oahu (in Pearl City).

Just a little bit about the Developmental Disabilities Division.

We serve people... with intellectual and developmental disabilities... qualify for our services.

And, as a state agency, we use federal and state funds to oversee a statewide system of supports and services for eligible participants.

Today, we have a full agenda for the 90 minutes that we'll be together.

So, we're going to go ahead and get started.

Just... wanted to point out for... the agenda... (that's on your screen)-- you can see that we're going to start off with a little bit of data... sharing... going into our introduction of our presenter... guest... presentation. And afterwards, we'll have a couple... sharing of information from the Epilepsy Foundation, and from one of our other guests here. Let me get us to some announcements.

Great. All right. Great to see so many of you attending today's training. We have about... 29 of you folks online, and a few in the room today. Really appreciate you folks being here.

In terms of announcements... this presentation is being recorded. So, we're in a hybrid format with folks in the room... and... on Zoom.

We have... participation statewide.

So, it's always great to use technology for that. So, thank you very much. Please feel free to add your questions to the Zoom Q&A tool.

You can find the Q&A either above or below of your Zoom screen-- depending on what device... you're using. And, we look forward to learning with you.

I do want to point out (just to get this out of the way)... that for the certificates of attendance... we will put the QR code up on the screen at the end of today's training, and you'll be able to scan the QR code with your phone. And, I'll also put the link into the chat-- so you can click there.

The evaluation form will have the option for you to request... your certificate of attendance for being here today.

Alright. And then, next... I'd like to share some data about the participants who receive services from the Developmental Disabilities Division.

This data... can help us to make a direct connection to the presentation topic... by telling us a little bit about who we serve and the individuals who are receiving services and supports who have also been diagnosed with epilepsy or seizure-related diagnosis.

The source for this data is our medical... electronic medical record system.

We generate this data... based on information that's shared at the time of intake and during the eligibility-determination process.

It's updated... throughout the course of service coordination... and person- centered planning meetings.

Usually, this happens with the participant and their case manager... families and guardians-- you know, people that are working together as circle team members... to make sure that the participant's plan... is up-to-date. So, let's take a look.

Okay. So, in fiscal year... 2025... there were approximately 3,500 participants enrolled services with the Developmental Disabilities Division.

Of those 3,500 participants, 813 (or 23%)... were identified as having an epilepsy... and / or seizure- related diagnosis documented in their electronic medical record.

Okay. In this chart, it tells us a little bit about the ages of the 813 participants.

So, the youngest participant is age two... and the oldest participant... is age 91.

In terms of the average... the average age of participants... with epilepsy or seizure... diagnosis was 38 years old.

And, the median age is 35. What you see on the screen here is a combination of the age ranges by category.

So, we have... 95 youth participants... ages 3 to 17.

We have... that's about 11%... of the 813... participants.

In the 18 to 25 range, there are 133 participants... or 16%.

252 participants are ages 26 to 39.

200 participants (or about a quarter of participants)... are ages 40 to 59.

And, another 133 participants are between the ages of 60... all the way to 91.

Okay. Then... in this next... chart... we're looking at county level data.

So, we can see in this chart... what islands... do the participants live on.

So, there are 19 participants that live on Kauai, 51 living on Maui, five living on Molokai, one on Lanai.

The majority (or 594)... live here on Oahu. And, 143 are living on Hawaii Island (on Big Island).

Okay. And then, the last data chart I want to share... this chart tells us about the participant's home care setting.

So, where do they live on the islands that they reside on?

Certified licensed home settings are those that are operated by non-family members.

These include adult foster homes... licensed domiciliary homes, and adult residential care homes.

There are 229 participants (which is about 28%) who live in these certified or licensed... home care settings.

It's not surprising... that we see the majority of participants... 564... (or 69%) living with family members.

And then, a much smaller amount (about... 20 participants) who live independently... in the community.

So, that's... just a little bit of data... to share with you all-- and, just in the context of this presentation topic.

And, we hope that this helps you to make a connection to... the topic and encourage you to be curious to learn more about how you can help support people... living with or receiving care for epilepsy and seizures.

Okay. So... question here: "Know what can we do to increase quality of life for participants living with epilepsy or seizure-related diagnosis?"

You know... we are all here today as one very good example.

We're here to learn-- to gain knowledge... through educational opportunities.

We all want to work... together as a team to support... the participant... and to get to know what their needs are... be proactive in addressing those needs, right? We want to prioritize... health and safety, and also just be supportive. Sometimes... being supportive means that we're being good listeners... and listening to what the participants... have... to tell us (whether that's verbal or non-verbal), and asking questions... you know to understand... their needs (using examples to make sure that you have the correct understanding), and being able to offer input into... their... individualized service plans.

Being able to monitor and document is also very important (as well).

So, each participant has a person- centered plan... that identifies what's important to and what's important for them.

And, you know, it shares information about who they are as individuals.

So, there's no one plan that we use... for every participant. It's all very unique and individualized.

The service plan... you... they really just outline what their needs, goals, and supports are.

So, it's very... personalized, but... really what we're looking for, right, is... to identify... all of who they are, right? What is... (you know) their journey? What is... the types of things that they're... working on?

What are they connected to in terms of resources (their lifestyle information).

So, these are like social supports. It could be maybe about their financial status, spiritual connections (if they have... any existing or they have a desire to make those spiritual connections), and technology supports.

So, all of this information gets updated regularly during visits with the... case manager, and the input... that's received... by people... by themselves and people that support them.

So, as a result of all of this... you know, comprehensive information sharing and putting it all together in the plan... is really having services that are matched up with what their needs are... and what their preferences are.

So that they can live meaningful... and healthy lives... and safe lives in our community.

Okay. So, this month... this month... in the month of November is Epilepsy Awareness Month.

Thank you all for being here... to spend this time with us. I want to next... introduce our presenter... and our special guests.

So... one of our presenter... I'm sorry one of our guests today... (who's in the room... I think)... is John Kelphie.

John is a national account executive with Jazz Pharmaceuticals.

His area of focus... is intellectual and developmental disability long-term care.

He really has a wealth of knowledge about I/DD... about residential, and... facility long-term care, epilepsy, seizure medications, [alternate] therapies... treatments.

And, he really... (you know) approaches healthcare conversations... (you know) with... education first... strategy.

I do… feel like he is a excellent listener. And, you know, just… (you know… personally just getting to know him).

I know that he… (you know) really genuinely cares about the… the communities that… he serves. And, we're really fortunate to have him.

So, as a fun fact… he…travels a lot (as part of his job). He represents… (you know) many of the western states.

So, Hawaii… we are just fortunate to be one of the states that he travels often to.

So, I appreciate all of John's efforts to connect us… as part of the Department of Health (with the Development Disabilities Division)-- just to connect us with these educational opportunities… that we're able to share with you today.

So… please… give a warm aloha and welcome to John.

Alright. Also in the room here is… okay… maybe she'll come back. Will she be back?

Missing one team member.

Presenter: Oh yeah, she's not coming.

Stacy: Okay, just checking… because I missed her. So, our featured guest… is… she recently joined Epilepsy Foundation of Hawaii as the executive director.

Toni Muranaka is here. She and her team have not wasted any time in getting the foundation moving forward.

They have been working really hard to increase… community engagement efforts statewide.

If you're not currently a member of the Epilepsy Foundation of Hawaii, I hope you will consider becoming a member.

By being a member, you'll receive updates. You'll be in a direct communication with them for… any of their activities… and all the resources that they… offer.

So, Toni will talk a little bit about that… later on… today.

Along with her here is… Reena. She is the foundation's outreach assistant.

She's back there. I think you can still see her back there. So, please give a warm aloha and welcome to Toni and Rita.

Okay. And then, for our presenter Dr. Julie Tuccillo. Dr. Julie Tuccillo-- she is a medical science liaison with Jazz Pharmaceuticals.

Prior to entering the industry, she was a pediatric clinical pharmacist at the University of New Mexico Hospital-- where she developed an expertise in various therapeutic areas (particularly epilepsy).

She has collaborated closely with epileptologists to standardize acute seizure management and optimize treatment outcomes for patients... in status epilepticus.

I'm very grateful... that Dr. Tuccillo is here... to present... this topic to us. I think you will find ... all of her slide content very, very interesting.

So, please give a warm aloha and welcome to Dr. Tuccillo.

Dr. Tuccillo: Hello.

Stacy: So, let me move over. Okay. So now I am going to... pivot.

So, I'm going to just... we're going to share our screen here. I'm going to pivot over to her. She's going to start talking, but... the screen won't catch up.

I'm going to let her... go ahead and start her presentation.

And then, I'm going to sit in here... but I'm going to be on the side-- just monitoring the Q&A and the... chat here.

Okay. Are you ready?

Dr. Tuccilli: Yeah.

Stacy: Okay.

Dr. Tuccillo: Hi everyone. Thanks for joining me!

I'm gonna present some basics about epilepsy today. So, as Stacy mentioned, I'm a medical science liaison, and I work for Jazz Pharmaceuticals.

Basically, what that means is... a medical science liaison is somebody who shares... information about medicines with doctors and other health care professionals.

I help explain how new medications work. I answer questions about them, and I make sure the medicine is being used safely and effectively in patients.

So, to clarify, I'm don't work in sales. I provide scientific information.

And today, I'm here to educate you. Alright, next slide.

So, here are our learning objectives today. We're going to learn about seizures, seizure types, and epilepsy.

We're going to discuss conditions that commonly occur with epilepsy.

We're then going to review the goals of therapy, and discuss emergency seizure management and post-seizure documentation.

But, my big goal today is really... (the first one) is to teach you about seizures and help you identify the different seizure types.

And, the work that you do caring for the participants is so important.

You're the ones interacting with them the most. You spend the most time observing them.

The neurologist is not going to be there to identify the seizure. It's up to you for... to advocate for their needs.

So, your work, your role in this is pivotal to the participants achieving better health and greater quality of life.

Without you identifying the seizures, the doctors cannot choose the right treatment plan... and maybe won't even know that one of these participants has epilepsy.

So, I see from the survey that most of you feel somewhat knowledgeable about seizures.

And, I think that's a great place to start. What I hope to do is not only strengthen that, but also leave you with an open mind-- because seizure presentation is so vast, so variable, and really so easy to overlook.

Okay... next slide.

So, we'll start with defining what a seizure is. So, here's how I think about it.

Our brains work like an orchestra. Millions of nerve cells send electrical signals in a coordinated way (like instruments playing together in rhythm).

When a seizure happens, that rhythm is suddenly disrupted.

Instead of organized signals, there's a burst of abnormal, excessive electrical activity.

And, depending on where this happens in the brain, the seizure can cause... changes in movement, awareness, behavior, or sensation.

Now, some seizures look dramatic-- like falling to the floor / to the ground, and then shaking. While others may be subtle, like staring... confusion, or just some unusual movements.

But, if you have a seizure, does that mean that you have epilepsy?

Well, seizures can be what we call "provoked" or "unprovoked".

There's various reasons you can have a seizure (without epilepsy)-- meaning a person without epilepsy can have a provoked seizure.

A seizure can be caused or provoked by things like low blood sugar, head trauma, infection, a super high fever, or illegal drug use.

So then, what is epilepsy?

Well, epilepsy is when you have two or more unprovoked seizures more than 24 hours apart.

There are other definitions here on the slide, but really what I want you to focus on is that epilepsy is two unprovoked seizures in a period of at least 24 hours.

So, now thinking about your participants… epilepsy is a very common neurological disorder. About one in 26 people will develop epilepsy in their lifetime. And…

But, here in your population (in the I/DD space), that's a little… it's going… it… those numbers look a little bit different.

Alright, let's… advance to the next slide. So, just to recap… seizures are sudden short bursts of electrical activity in the brain that disrupt normal brain activity…and can cause involuntary changes in body movements, in functions, behaviors, and conscious awareness.

A seizure is an event that can indicate that other medical problems exist (that this person has other medical problems)… whereas epilepsy is a neurological disease in which they have seizures.

So, remember, not all people that have seizures have epilepsy.

Alright…next slide.

So, what you're going to see on this slide here is on the horizontal line, you have the age of the participant.

And then, on the vertical line you see the incidence or how common epilepsy is according to age on the line. Okay.

So, what we see is that in the pediatric population (the younger population)… we see that there is more… prevalence of epilepsy.

Okay. More pediatric patients have epilepsy. Then, as they age, this goes down. And then, as you get to age 60, this comes back up.

So, more people that are pediatric, and more people that are elderly have epilepsy.

But I… thinking about this graph and thinking about the people that you care for… and maybe this doesn't quite jive for your particular patient group.

So, this is epilepsy in the general population. But, my understanding is that population you care for is really the I/DD population.

So, across all ages in the I/DD population, we see more epilepsy at every age.

We also see... as the severity of I/DD increases, the prevalence of epilepsy also increases.

Okay, next slide.

So, a person can get epilepsy from various causes.

They can get epilepsy from infections, genetic causes, metabolic reasons. And, I know what you're thinking. I just said that infections can cause a provoked seizure, and provoked seizures are not epilepsy.

Well, that is true. And, they can also lead to epilepsy as a long-term complication.

So, same goes for head trauma. So, you get an acute injury of the brain... and that can cause a seizure.

Then, as the brain heals, it maybe can have some scar tissue.

The healing... after the healing process is complete and things have resolved, the brain itself may be changed to some extent-- where you can end up with a long-term complication of epilepsy.

Alright. Epilepsy (as I mentioned) is more common in individuals with intellectual and developmental disabilities... primarily because both conditions stem from the same underlying causes-- such as abnormal brain development or brain injuries that occurred early in life.

These shared causes (which can include certain genetic conditions or birth trauma) create an electrical storm... in the brain that results in both intellectual disability and seizures. Okay, next slide.

So, this is where we're getting into the most important part of the discussion. We're going to go through different... next slide.

So, first I'm going to explain the difference between generalized and focal seizures.

So, generalized means the seizure starts on both sides of the brain, and focal means it starts on one side of the brain.

Now, you can have a focal seizure in one side or the other, and it can progress to where it involves both hemispheres of the brain. So, it can go from focal to bilateral focal to generalized. Okay... or it can just stay focal.

So, okay. Next slide.

So, getting to the nitty-gritty of it, here are our first two seizure types. These are both generalized seizure types-- meaning they start in both sides of the brain.

They're much more subtle than you might think. So, let's talk about atonic seizures.

These are sometimes called "deep seizures"... sometimes called "drop attacks". And, I'm going to show you what this can look like.

It can be... it's... basically a limpness--a loss of muscle tone. So, it can just be a head drop.

Could also be a lot more pronounced... like a falling forward. They might hit their head.

They might fall to the ground. Okay. Now, you see in this picture... you see someone in a wheelchair wearing a helmet. And, that helmet... is there to protect their head from head injury. That's always our biggest concern is that we're going to have a head trauma from falling.

So, there's the helmet, and they're in the wheelchair.

They may be in the wheelchair because... not necessarily because they need help.

They have trouble walking. They may be in the chair because they see so often... that their fall risk is high all the time. And, so therefore... they are in the wheelchair. Okay.

Now, these seizures typically last around 15 seconds. Let's talk now about the other seizure type on the slide called "tonic seizures".

This is basically the opposite.

So, atonic is a lack of muscle tone (atonic).

Tonic is an increase of muscle tone. So, this is going to be a stiffening of the muscles.

So, this can look more like extension and a flexion. It can be the leg straightening. It can be different parts of the body.

But, whereas we have the atonic... is the drop, the limpness. The tonic is the stiffening.

Now, these seizures often happen during sleep, but can also happen when the participant is awake.

They can also lead to falls. These are sometimes also called drop attacks / drop seizures.

They're also short in duration (usually around 20 seconds).

And, I want to pause here and ask if anyone wants to share with me any experience having seen either of these seizure types.

[Microphone Noise]

Anybody online want to share? You can raise your hand... in the Zoom screen, and I can un-mute you. Want to share? Anybody in the room?

Participant: Yeah, my son used to have the tonic seizure when he was younger.

But now, he (about a year ago) started dropping… falling (you know) backwards.

Dr. Tuccillo: Okay.

[Inaudible]

What happened? What did his tonic seizures look like?

Participant: You know… this shaking.

Dr. Tuccillo: Shaking.

Ok… thank you for sharing that with us. Alright, let's go to the next slide.

So… I bet a lot of you have seen this one (or know of this seizure type). This one is a very dramatic presentation of a seizure.

Okay, much more dramatic than the atonic or the tonic.

Again, this one is generalized. So, it's both hemispheres of the brain.

So, this one looks like the tonic seizure that we just talked about. It's that stiffening of the muscles, stiffening of the body.

But then, it goes into what we call the “clonic phase” with some rapid rhythmic jerking.

So, first the tonic phase happens. The muscles stiffen, the person loses consciousness, and falls to the floor.

Then comes the clonic phase-- which is the arms and legs moving rapidly and jerking.

The person may have some additional signs of drooling or losing control of their bladder or their bowels.

Okay. These often last one to three minutes.

Alright, next slide.

Some of these seizure types are more subtle. And, this is where we really need your help.

So again… generalized seizures… both sides of the brain for these ones as well. And…

So, did you catch that? Like a staring off into the space-- kind of going… off into a place where you can't connect with them. So, just staring spells, or a look of confusion… is often what we see in an absence … seizure. They can also be some eye fluttering.

It's sometimes looking off up into the corner, and sometimes fluttering of the eyelids. Okay.

Now… this typically lasts for 30 seconds. The person is not aroused well at this time. You cannot get their attention.

They don't know what's happening. They don't know that they're having a seizure.

They will often come right back, and restart whatever they were doing before the seizure, and not know that they even paused and had that seizure.

The myoclonic seizure type is also subtle, but quite different. So, this is a sudden uncontrolled jerk. Okay, this is... this might even look like a movement that they meant to do on purpose.

It can look for it... look like a purposeful movement... but not always. So, it can just look like an arm thrust. Okay. And, it's... a sharp quick movement. And, I think that's why it's... commonly overlooked is because it's... it happens so quickly. And then, the participant can go right back to what they were doing.

These often happen during the time of awakening-- so in the morning or maybe after a nap.

But, they can happen at other times of the day. The person is not... is typically aware that it happened.

But, they don't have control of it. Now, because they're so brief, myoclonic seizures can look like an everyday action-- like a startle or just being clumsy. And, that's often why they're missed.

But again, this is where your role is pivotal, and that you are in the right place to advocate for the participants.

And, you are paying attention to these signs that may help connect the participants to more specific... neurological services that can really help them improve their health and their quality of life.

Alright. And, just to give you an example of a myoclonic seizure, a patient once told me that every morning she uncontrollably threw her hairbrush across the room.

Okay, so she just had this one and she didn't... this one movement and she didn't know why she was doing it.

She hadn't been diagnosed with epilepsy and eventually the neurologist had figured that out (together with a... participant and her family) that that was what was going on.

That was why she was throwing her hairbrush. It happened in the morning. She's brushing her hair, and that was how she... that helped her diagnosis of epilepsy.

Okay, next slide. Now, here we are talking about focal onset seizures.

So now, we're talking about a seizure that starts on one side of the brain, and it [can] start in either side of the brain.

And, these can be aware or impaired -- meaning consciousness is aware or not aware (impaired consciousness).

So, focal aware means the person is alert and knows what's happening, versus impaired... where they are unconscious (don't know).

This can just be a shaking... be a twitching. It could be a shaking of the foot. Okay.

It also can be... subtle movements. It could be tugging. It could be picking. It could be picking their hair.

But, in general, not necessarily a huge movement. So again, [it] can be a little bit subtle.

It could also be sensory or an emotional episode. It can be changes in taste, smell, vision.

It could be feelings of joy or fear... could be nausea. They typically last less than two minutes.

Now, for focal impaired seizures (meaning that they are not aware of what's happening), they won't... they don't know that they're seizing. When they're done seizing, they don't know that they had a seizure.

Okay. This... they can sometimes have these... automatisms-- meaning that they have like a twitching of... usually a facial twitching... like a lip smacking... like moving of their mouths (can be chewing, lip smacking, and other movements like that). Alright.

Now, these focal seizures can evolve from the one side of the brain to both sides of the brain.

And, they can go from focal to generalized. And, they can even advance to a tonic clonic seizure (like we looked at before).

They typically last between one to two minutes.

Now before I move on, I want to tell you about my new friend, Abby. I met her just this week at Epilepsy Awareness Day at Disneyland.

And, Abby is 23, and she's finishing up her master's degree in neuropsychology, and plans to attend medical school and become an Epileptologist.

Abby was diagnosed with epilepsy at age five and she has focal seizures.

Abby has these... feelings like... before she has a seizure, she can sometimes know that something's off. She doesn't feel quite right.

She was on the track team and at one point she wasn't feeling quite right and so she left track practice.

She went to the locker room. She went to the locker room, and had uncontrollable laughing and uncontrollable crying.

She wasn't... in a position to verbally communicate.

She cannot say what's going on, and she actually doesn't even remember these episodes ever happening.

Okay... these are focal impaired awareness seizures, and for her they sometimes to a generalized tonic seizure.

Now, remember, she just ran off to the locker room, and so now she's alone.

After laughing and crying in her impaired focal seizure, if she progressed to generalized tonic seizure, there is nobody around to help her... be safe, put her in a safe position. there's no one there to... determine if she needs a rescue seizure medication. Okay. And then, after she is ... her seizure has resolved (or has completed) and... is going away, she would vomit. So, she's in the locker room now vomiting. Okay.

Now, this is a 23-year-old woman pursuing advanced education.

I wonder if any of you can tell me about a similar situation with an I/DD participant that (you know) maybe was... a surprising presentation-- something where you didn't think was a seizure, could have become... actually was a seizure.

Does anyone have anything to share on that?

[Background Noise]

No. Okay. Alright. Let's move to the next slide. So, what do you think?

Does epilepsy occur by itself, or there typically other conditions that occur with epilepsy?

Typically, other things are happening as well. So... next slide. So, some common... medical conditions that happen with epilepsy-- hypertension, diabetes, stroke, depression...

Lots of different other medical problems happen... to people with epilepsy. Alright, next slide.

So now, I understand that we have... some pediatric participants.

And, what we see in these comorbid conditions (these co-occurring medical conditions)-- they're different in the pediatric population typically than they are in the adult population.

So, we see... attention... we see... hyperactive... attention deficit disorder (ADHD).

We see autism spectrum disorder (ASD).

We see developmental delays, developmental difficulties, and... migraines (lots of different... co-occurring conditions).

But, this is... these are the typical ones that we see in the pediatric population. Alright, next slide.

Now, in the elderly population, we see... all kinds of medical conditions... at a higher rate. Okay.

But, you know, so a lot... elderly people often have trouble sleeping. They often have depression.

But, elderly participants that also have epilepsy are more likely to have all of these conditions... (or some of these conditions rather). Alright, next slide.

Alright, so epilepsy increases mortality by three times.

One particular risk for us to talk about is SUDEP-- sudden unexplained death in epilepsy.

Hopefully, none of this... hopefully none of you have seen this in your participants.

But, I wonder if anyone is familiar with this. You... good, I see some head nodding.

So, I'm glad to hear that some of you are aware. I do think that this is something that we don't talk about enough.

And, some people in the epilepsy community are very much unaware of this as a risk of epilepsy.

So, let's talk about it some more. Let's go to the next slide.

So, SUDEP is a death in a patient where... that has epilepsy... that is not caused from trauma... drowning...

It's not caused from status epilepticus-- what we call a really prolonged seizure or any identifiable cause. Okay?

This is actually the most common cause of seizure- related mortality in patients with chronic epilepsy.

There's some risk factors for this-- uncontrolled or frequent seizures, generalized tonic clonic seizures, and failure to adhere to anti-seizure medications. Okay. Now, I think that you're all uniquely positioned in this care setting to really decrease this risk.

So, from the list of risk factors, you can help participants who have uncontrolled seizures.

If you have a participant in a home and, you notice that they start having more frequent seizures than they had before, this is something for you to speak up about.

This person had three seizures today. They don't usually have any seizures.

This is something to notify a care team about. Okay. Also... if they are not... taking their anti-seizure medication, (you're having a hard time getting them to take their medication), this is something to report as well-- because these are risk factors for SUDEP, and you absolutely can play a role in helping notify the care team that they have these risks for SUDEP. Alright.

Let's go to the next slide.

So, here we're going to talk about goals of drug therapy in epilepsy.

So, of course, what we want to do is decrease the seizures, right? That's our number one thing is... let's have less seizures or no seizures. That would be even better.

Well, whenever you treat a condition, you want to balance the treatment with the risk of the treatment.

So, the treatment... and the side effects of the treatment.

So, again, you are in a position to advocate for your participants.

So, you might notice changes in a participant that occurs with medication changes. Maybe the person is more sleepy.

Maybe they have become constipated or have diarrhea since starting a new medication, or since increasing or decreasing the dose of a medication.

You might see these kinds of changes.

Maybe they've lost weight. Maybe they don't seem to feel like eating. They might have had a change in their mood, in their behaviors. They may have more aggressive behaviors. They may seem depressed.

All of these different things are things to consider when you know that your participant is going through medication adjustments.

It is an opportunity for you to think about what changes you're seeing in them... and document that so you can notify the care team.

I wonder if this is a side effect of the medication changes that you're doing. Okay. A lot of times side effects go away on their own, but sometimes they don't.

So, it's just an important way for you to advocate for the participant.

And then, the last goal of treatment is ultimately to improve quality. Alright, next slide.

There's a lot of FDA approved medications. There's over 30 of them.

And they've, you know, over the course of time, we have changed which ones we typically use first (and all of that). But...

So, you'll see lots of different anti-seizure medications in your participants. Alright, next slide.

There's also other ways to treat epilepsy than just medications.

Some patients are on what we call "a ketogenic diet". So, a high-fat content diet, low carbohydrate diet.

There's different forms of this high-fat diet. There's an Atkins.

There's all different kinds of forms. But often, they require counting carbohydrates throughout the day. So, you may have seen that, you may see that at some point.

There's also devices that can be implanted in the participant's brain and have parts of it in other parts of their body. So, there's something called "VNS"-- vegal stimulation device.

And, basically, this is a device that will help the electrical firing of the brain.

And, it has a magnet in the chest. So, you have this... you have this magnet that you swipe over this part... of the device that's in the chest, and that can help stop a seizure.

There's other devices similar that monitor the electrical activity of the brain and then start to fire different electrical signals... to stop the... that over-firing of electricity in the brain.

And then, there's also brain surgery. Some of your participants may have had part of their brain removed, or had a laser put in to just pinpoint one part of the brain. Okay... so lots of different approaches other than just medications.

Alright, next slide.

All right, seizure emergencies. Let's talk about status epilepticus for a minute. And, as I mentioned before, that basically is a prolonged seizure.

So, we typically define that as a seizure lasting more than five minutes.

But, it can also be when there's three or more seizures very close together, and the participant has not regained their normal state of consciousness between those seizures.

Now, this requires medical treatment in a hospital setting.

Sometimes, you can treat early before you get to a hospital-- depending on the rules of your facility, and depending on whether or not the participant has what we call "a rescue medication" (which we'll talk more about in a little bit) you may be trained on some of these medications.

But, I wonder... if any of you are familiar... (hopefully familiar) with your medical... your emergency medical services policies, and what you are supposed to do when something like this happens. Does... has anyone ever had to call EMS for a participant before?

Participant: Lots.

Dr. Tuccillo: Lots... okay. Have you ever had to for a seizure?

Participant: Yeah, it's easy for seizures. I mean, he has five minutes or longer seizure.

Dr. Tuccillo: Okay. Did... the participant have a rescue medication?

Participant: Yeah.

Dr. Tuccillo: What kind of medication was it?

Participant: Uh... yeah. I got it written down.

Dr. Tuccillo: How did you give it to the participant?

Participant: Usually in the mouth.

Dr. Tuccillo: In the mouth. Okay.

So, was it like in the cheek or under the tongue or...

Participant: On the cheek.

Dr. Tuccillo: Okay... okay. So, we call that a buccal administration-- where it goes in the cheek. Okay. Very good. So... so sometimes you may see that. Now, in pediatrics, it's often a rectal medication. Okay.

And then, in a lot of times it's an a nasal medication. So, it's a nasal spray that you give. Okay. Which is... a really nice easy way to administer it. And, it also works very quickly.

And, of course, any medication that is used for seizure rescue, you want it to work very quickly.

Alright, next slide.

So, here's a little bit more about... rescue medications. Alright, so they are fast acting.

We want them to get into the body quickly, and we want them to stop the seizure quickly.

And... so some of you may have had participants that have particular rescue medications. Alright, next slide.

Now, after a seizure, you've got a lot of things you've got to think through and write down.

And, in an ideal world, you would be able to document what happened before the seizure, what the seizure looked like when it started, how the seizure changed over time, how long the seizure lasted, and what happened after, and how long it took the participant to really recover from that seizure.

Now, that's a lot. That's a lot to remember. And... all of that is helpful information.

And, what that might do is, you know, what happened before the seizure?

Well, maybe you can help show that the participant actually has an aura. What we call an aura is... it's... means that they know that the seizure is coming.

There's something going on in their body that tells them something's going to happen (I am going to have a seizure).

Now, that participant may or may not be able to communicate that to you. Okay?

So, I met in... (when I was at Epilepsy Awareness Day at Disneyland), I met an epileptologologist who told me that they had an I/DD patient, and they believed that they had an aura, and that when they had the aura, the... they had this particular behavior.

They would slam their head on... on a table or a wall. So, they would have this self-injurious behavior.

They believe that was because the patient felt agitated... felt anxious because of an aura.

So, they'd have their... they'd hit their head, then they would have a seizure, and then they would come out of it. Okay?

So, things that you may not think of as maybe... something linked to a seizure.

You might think of that more of a behavior, but that behavior may be linked to a seizure.

Alright. So, moving forward... action plans.

So, hopefully some of you are familiar with a seizure action plan. So, since you had shared about giving a rescue medication, can you tell me... did that participant have a seizure action plan?

Participant: Yeah.

Dr Tuccillo: Excellent. Very good. I like hearing that.

And, I am a little opinionated about this, but I think that really anyone who has epilepsy should have seizure action.

It really is... a link from the doctor to the caregiver on what to do when this happens.

So, part of that seizure action plan is really just going to be basic... seizure first aid-- where you position them on their side (hopefully on the floor) so that they... and you move things away... and so that they are in a safe place.

And then, ideally, there's a rescue medication-- you know where it's stored, how to give it, and how long to wait of the seizure before giving it. Okay.

So now, typically it's 5 minutes. That is the typical way that you give a seizure rescue medication.

But, some participants... maybe they don't have a seizure that just continues.

They may have seizure clusters.

So, sometimes it's a clustering of seizures.

You may see instructions that say something like "three or more seizures in a one hour period, and then you give the rescue." Okay?

There's quite a lot of variability of seizure presentations and also of what we call "status epilepticus".

So, some participants… maybe their seizures (when they have them) are so bad maybe that the… doctor wants you to give that rescue medication at the very beginning of the seizure.

If you're in a rural area where you cannot get to emergency medical services in a timely manner, they may want you to give that medication right away.

So, ideally, everybody has seizure action plan… and you know exactly how to give the medication and what to do after. When do you call 911?

All of that should be listed in the seizure action plan. Okay… next slide.

So, here are some additional sites. These are some resources for you to check out.

And, one of them is the ILAE site. And, that one is particularly good to watch videos of seizures so that you can get an idea of what they may look like.

But again, remember… this is a vast diverse presentation of like seizures can happen… looking so differently in different people and the different seizure types.

So, just try to have an open mind, and just try to be observant and think about… oh that's different.

I haven't seen them do that before… or I see the pattern of… oh, I now notice that… when they are watching too much TV…. that they start having twitching.

Maybe (you know) TV could be a seizure trigger for them (you know). So, these are all things to just… kind of keep in mind as you're going through these activities with your participants to just help… help be their eyes and ears. And then, of course, their mouth by advocating for them.

Alright… last…let's go to the summary slide.

So, just to sum it all up, not everyone with seizures has epilepsy. You can have provoked seizures… or you can have epilepsy (which is a neurological condition which… you have seizures).

A seizure is a sudden short-lived burst of electrical activity. It causes involuntary changes in the body, movements, could be bodily functions, behaviors. It can affect conscious awareness as well.

Now, people with epilepsy have a wide range of other health… conditions.

And, when we treat epilepsy, our goals are to reduce the seizures and also minimize the side effects of the medications or other treatments.

Immediate medical help is needed for seizures lasting more than five minutes.

And, it's important to note what happens before, during, and after an event. As soon as possible, document that so that you can help the care team identify the seizure type, and bring that participant to the most appropriate treatment.

And… that's it. So, thank you very much for your attention today.

[Background Noise]

Stacy: Position back over here.

Oh, tada! [Laughing] Okay. Thank you so much, Dr. Tuccillo.

So, okay. So, I know we have questions… that we received during… the registration process for those that called me and submitted with their registration

online. So, thank you very much for all of those questions.

We will… do our best to get to… some of them… at the end of our presentation time.

Now… if Toni's ready, we're going to go ahead and stop… sharing on my screen and…

Toni will go ahead and share on her screen. And, let me try and [inaudible] her in here. [Clears throat]

Okay.

You got it?

Looks good. Okay.

Toni: I'm getting good at this.

Stacy: You are…

Toni: Finally!

[Clears throat]

Stacy: Big [inaudible] on my face.

Toni: You don't need my face.

[Crosstalk]

Toni: Oh, it says join audio.

Stacy: Oh, no. Just click the leader link, and go ahead.

Toni: Oh, hi everyone! Aloha everyone. My name is Toni. I'm the CEO of… the Epilepsy Foundation of Hawaii. And, first, I just want to say I'm so thankful that… we have Jazz Pharmaceutical… that really connected… reconnected us to the Department of Health.

And, it's so important to have these connections / these partnerships-- because that's how we grow and expand… and just really… touch into the community and… do the help that we're here for. So, thank you so much for having me here.

The message you see on the top, it says no one faces or should face epilepsy alone.

You know, that's more than a slogan. It's a promise for us.

And, because every story deserves understanding. That's, you know, with today's medical advances, many are being rewritten.

Stories… you know, are just… we're just starting to heal… the progress and renewed life.

So, why we're here? We are just doing our very best to… help because there… there's a delay here.…

1 in 10 people will experience a seizure in their lifetime. And, that is a lot.

And then, also… 1 in 26 will be diagnosed with epilepsy.

And, I know the slides are coming up a little delayed, right? Okay…

There you go. And so… (you know), it's… it comes without warning.

One of the things that really… was mind-boggling for me was that seizures are one of the top three medical emergencies in schools.

When I heard that, I… I'm like… you know, our organization has to do a lot to go into the schools. And, so often, those around them at school doesn't even know what to do.

And, so that's why we're here. And that's why our organization exists.

So, my question to everyone is: "How many types of epilepsy are there?"

And, I didn't know this before. I started with the epilepsy foundation… back in January.

So, still this year. So, I'm still learning a lot., and really there are a lot.

So, in your mind just guess how many epilepsy… types of epilepsies there are. So, I'm going to go through this.

So, there's focal. So, there's four main categories. There's focal-- and that starts in one… one side of the brain.

And then, there's generalized epilepsies (affecting both sides at once).

And, there's combined generalized and focal-- which is a mix of both.

And, there's combined generalized and focal epilepsies.

And, there's unknown or unclassified. So, if you guessed that there's over 40, you win. Well, nobody really wins.

But, there are so many different types of epilepsies and there is a shortage in... neurologists and epiletologists... that we really need to... get with the program here and just do a lot more.

So, that brings us to say... or ask us what is Epilepsy Foundation doing here in Hawaii?

So, we have a very small but mighty crew. It's just me. I'm the only employee.

And, I have... a lot of wonderful volunteers, and I have a few contractors. And, what we're doing is we're rebuilding right now-- because we've been around since 1971. That's 54 years strong.

And, our mission is simple. It's to empower individuals and families affected by epilepsy through education, advocacy, and community support.

And, why we do this? Because, there's over 15,000 people in Hawaii with epilepsy and 2,000 of those are children.

So, we really need to go back into the schools.

And, what we're doing, we have programs like the E-Kōkua Club. It's a new club. I'm going to talk about that next.

And then, what we did do... is we joined a national helpline.

The helpline is... has been around for many years with the Epilepsy Foundation

And, we just joined them this past August.

And so, we get calls... from all over the nation. And, it works out really great because we have the night shift.

So, we're from 10:00 a.m. to 3:00 p.m. So, we have 5 hours of calls informational... some are suicidal.

We were trained / certified... and it's a wonderful opportunity for us to go into the community... and not only in Hawaii but nationwide.

So, we are truly helping the communities make a difference across the country.

And so, that leads perfectly into one of the projects that we're doing right now.

And so, that's the E-Kōkua Club that I talked to you about. So, "E" in Hawaiian means "the."

And, Kōkua means "to help and to support." And so, it's a free club.

So, we'll have lei-making, hula, ukulele, painting. And, so all of this… we're planning for 2026.

And, we have two organizers that are helping to handle this… one on the Honolulu area, and the other in the Northshore area.

And, to keep all of this together, we created (or we're in the midst of creating) a new app.

So, this app will actually bring people together… help them to organize their safe space… and just really help to monitor… all the different activities that are going to be happening.

So, there's a lot of moving pieces I have going on.

But, I know it's all going to work out-- because we're doing it for a wonderful reason.

And so, there's stories. The stories really connect all of us.

So, we created something called a wall of flame. And so, the first picture you see here… meet Donna.

She's our board president. And, she is such a humble lady. She works for the… for First Hawaiian Bank.

And, she's been with the organization for (I think) a few decades.

And, I had to beg her to be the president. So, now she's our president. And, she… this was her idea to make the wall of flame.

And so, if you were to go on the QR code and scan it, you would see… or read all the stories… all the wonderful stories… that actually… push people to help one another.

Because, you're really not alone. So, if one of you wanted to be on the wall of flame… just please text me, and we can get your story ready and ready to go. So, if you want to just take down my number… (808) 528-3058.

Again, the number is (808) 528-3058. And, we can get you on the wall of flame.

And, like I said, we're not stopping. We have a wonderful… opportunity here for a… educational game.

And so, with my mind (I'm always wanting to create)-- so, I created something called "Epilep-SEE".

So, it's a wonderful way… to have a… all your family get together or friends and play a game similar to Uno… and on those cards is just… expressing emotion.

So, a lot of times when you have epilepsy, you're not able to connect with people because you don't really… you're not able to share how you feel.

So, this... is one of the games that we're helping to... create.

We just applied for a trademark for the "Epilep-SEE" name, and that takes about six months.

So, if you are interested in getting your hands on this game (be one of the first), you can go to our website (not this week, but next week), and we're going to have a signup sheet.

And, I'm going to start... gathering names and numbers so that way we can... go ahead and get you on our list. We're hoping to get these cards into all the hospitals.

And, it's going to be for the newly diagnosed... families.

And, like I told you before, I have another thing-- it's called the Sofia collection. So, you know those wonderful...

Aloha Collection bags? Well, we're partnering with them, and we're creating a wonderful designer bag.

And so, this design honors our teen advocate Sophia Owen-- who represented Hawaii in Washington, DC earlier this year. She met with legislators and... you know, just to raise awareness in Washington DC for epilepsy. So, we called it... crown of strength... and it's inspired by the crown flower. And, the crown flower is purple (which is perfect).

That's our color, and it symbolizes resilience, grace... and the word crown really means "head".

And so, that's where the storms begin. That's where epilepsy storms begin.

So, yet like the flower (you know), strength and beauty continue to bloom even through

life's challenges.

So, this collaboration not only celebrates Sophia's courage and advocacy, but it also honors every individual living with epilepsy through Hawaii.

So, one of the designs we're going to do (if you see the design there with the with the bag), we're going to change that leg to be different types of crown flower-- some open, some closed, some purple, some white. And, that shows the different stages or the different types of epilepsy, and the different types of people.

So... just so you know, there's only 200 bags. Okay.

Participant: 100.

Toni: Oh, there's Oh, there's only 100. [Laughing]

So, the... so once these bags go... that's it.

So, if you're interested in ordering, you can click on there… the QR code and we also have a… QR code on the… on the table there.

And one last thing, Sophia Owen, she just… right now she's attending… college in the east coast, and she has her eye on medical school to become a neurologist or epileptologist.

So, we're very proud of Sophia. So, that's why we needed the Sophia Collection.

Okay, so back to business. Resources…. everyone needs resources, right? And, that's why we're here.

So, one of the… one of the forms here (you're going to see) is a seizure log.

And, that is where… (you know) doctor was talking about how important it is to log everything.

And so, we have this… seizure log and if you're able to just jot down everything it's going to really help your doctor to… disseminate… to give… to prescribe the right medication.

So, we're going to be getting this on our website, but there is a QR code right here. So, you can download that if you're watching online.

The next one is a… the action plan that we talked about.

And, in some of the… I think the folder that you folks have has an action plan in there.

So, you can do that, and if you need to download… one that you wanted to do it online… it's a fillable PDF.

You can go and download that QR code, and you can get that…in your hands.

Okay.

[Background Noise]

Okay. And, the seizure first aid plan. The seizure first aid plan is a wonderful… form (and not a form, but it's a wonderful flyer) that I feel should be in schools.

It should be in heavily… trafficked areas. It should be in health rooms, etc.

So, that… seizure first aid plan you can actually download it with the QR code that's on your screen, and… it's a value to our community (it really is to have something like that).

And, last but not least, our action plan. We always need to have an action plan-- because everyone has goals. And, why we are here… we're here to educate the community.

We have a free conference that's on the 22nd-- which is… not this Saturday but next Saturday. It's coming up you guys. So, we have… it's going to be at the Aloha Tower.

They're going to have three wonderful doctors: Dr. Stein, Dr. Duga, and Dr. Wysinski will talk on three different subjects, and then they will form a panel to answer your questions and address your concerns. So, it's going to be from 12:45 to 4:30pm. There's going to be light refreshments.

The conference is free, and we will cover parking.

We ask everyone to register-- as there are a limited amount of seats. I think... the room that we have only holds 150.

So, we would love... I would love to see you there that I can meet you in person (for those who are online).

And so, lastly, I just want to say I'm very, very grateful.

I'm very grateful for this connection, and I'm looking to do more for the community, and... (you know) my hope is that today we lit... our flame of light... so no one faces epilepsy alone. So, thank you so much for having me.

Stacy: Excellent resources! Thank you so much. I'm so excited. Free conference. Come join us!

Okay, we have... a good amount of time left. So, I am going to... share my screen.

John's gonna... come. I think you still can still see him in the camera, but he's there.

He's going to...

John: Actually if you can... if you don't mind answering the questions, some of the questions that... for the presentation, if there's time I can always comment.

Stacy: Okay. Okay.

John: Let's address that first. Yeah.

Stacy: Okay. Let me get to some questions.

[Inaudible]

Okay.

[Inaudible]

Right. Okay. So, questions. Let me get it up here.

Okay. Questions. Okay. Is there a general seizure plan that fits most people?

What to do if a seizure occurs? Often agencies have generalized seizure plans.

So, I'm just going to read... questions. Dr. Tuccillo or... Toni or John, they can all jump in... and answer if they would like to.

What do you think? Generalized seizure plan that most people... or what to do if a seizure occurs.

Dr. Tuccillo: So, in sense of a rescue medication, the usual... instructions would be... is give the rescue medication in five minutes.

Okay? So, you know, you have the seizure, the seizure starts, you check the time, you go get the medication, and then you wait till it's been going for 5 minutes, and then you can administer the medication.

It's... and then after that, you typically call 911, or you call before you give it (either way).

It'll specify all of that in the prescription. But, sometimes there's seizure clusters. So, it may be three... seizures in a period (that it will clarify for you). So, it's... often an hour (like three seizures within an hour).

And then, you give the rescue medication.

So, that... and then there is the basic first aid (seizure first aid) that Toni shared and that you should all become familiar with-- which is basically how to position... a participant when a seizure is happening, and what to do to... give that person a protected space (so that they don't hurt themselves).

Okay. How about... this question? If a participant is having seizure activity, you mentioned about five minutes... but should we call the hospital or should we call for emergency response (if a lot of little seizures or if it go only goes beyond five minutes)?

Dr. Tuccillo: So, this is why a seizure action plan is so important for every participant--because these instructions really can be different from one person to another (depending on their seizure type).

Sometimes... participants may have an epilepsy syndrome that is more difficult to treat than others.

So refractory... they may have a refractory form of epilepsy. Sometimes, that... can mean that once a seizure starts it's really hard to get it to stop.

So, sometimes a participant may have those instructions of... as soon as the seizure starts... call 911 and give the medication. And sometimes... you may be... your location may be far away from emergency medical care.

So, the provider... the doctor may want you to call 911 right away, and have a... emergency medical services start coming to you right away.

So, really it depends on the situation. Ideally, everybody has a seizure action plan.

And, that is something that you all can advocate for all of your epilepsy, your participants with epilepsy to have.

Stacy: Got it! Okay. This question… "Is there any way to recognize an impending seizure in a non-communicative adult… before the seizure occurs, and how long before occurrence?

Dr. Tuccillo: So, this is something that really varies, right? So, this is part of our vast variable presentations of seizures.

Some seizures have that aura (that I mentioned) where the participant can feel it… and this… their expression of that can be vastly different.

So, I mentioned the example where someone was hitting their head over and over again. You might see an emotional response.

You might see inappropriate laughing.

Maybe they start laughing, and there's nothing that you can connect this laughing to.

They might start crying. There's lots of different… you might see them start throwing up.

There's such a variety of presentations, but this is where you come in as the observer… is to see… "Oh, well, right before the seizure, this is what happened".

And then, maybe when that seizure occurs again, you might see the same thing or something similar.

So, that's why that documentation is really important-- so that you can help identify that.

Then you can tell the care team "This is what I saw. This seems to be a pattern for this person."

Stacy: What are some of the techniques for assisting someone with seizures who is bigger than yourself?

For example, I'm petite and my participant is 5 foot 10 and weighs 220 pounds.

So, we… did discuss this and… I can relate (because I'm a very small person), and… this would be a difficult situation for me to handle.

Basically, you want to get that participant down on the floor (ideally on their side).

You want to clear the area so that as they're moving their bodies, they don't cause other things to fall on them.

How to get them on the floor in a… while you are keeping yourself safe and safely doing that for the participant…

I am not familiar with techniques about that.

But, Toni had brought something up. Did you say that you saw some... a video about that?

Toni: Yeah. Yeah.

Dr. Tuccillo: Excellent.

Toni: Right, it... I was explaining he looks like Tai Chi-- because he was so careful and he was just... he was just doing his thing, but he was very ginger, you know. He did it very carefully. So...

Stacy: Question about medications: "What patient is ideal for using Epidiolex? I'd like to learn more about treating seizures... with Epidiolex."

Dr Tuccillo: Well... Epidiolex is FDA approved for seizures associated... with Lennox-Gastaut Syndrome, Trabey syndrome and Tuberous Sclerosis Complex.

Those are three specific epilepsy syndromes. Okay. And, to be diagnosed with those epilepsy syndromes... that would be done by a neurologist or a epileptologist. And so, now that it's seizures associated with those three syndromes-- which is kind of a vast set of reasons to use it because it... covers a lot of different seizure types.

Typically, you would start Epidiolex in those patients with those seizure types (you know) after they had failed other medications.

Now, it doesn't have to work that way. But... typically you're using it for treatment refractory epilepsies.

And, I think this is maybe a good time for you to chime in Sean.

Sean: So, I sit here, or do I... sit here?

Okay. Yeah. the... so very good question.

And, I have here all this... all these presentations for the last couple days. and there's one thing in common.

And, that is... is that people have shared experiences of seizures that they're seeing.

People are sharing experiences of their (you know) who they care for, and how these seizures look.

But, everyone has not... no one has shared what they're trying to do about it.

In other words, how are they going to be able to make that better or less seizures, more controllable?

So, as Julie was mentioning, it all has to do with the word "refractory". So, if you're asking what is the right patient... or resident for Epidiolex, is someone that is continuously demonstrating the same level of seizure type with no improvement.

That's probably the best way to describe it.

So... and there's a tool that the state department has that I encourage everyone the audience... present here (and the one that it's on Zoom) to really... ask... Stacy to... share send it to you guys.

It's called the REST tool. It's called refractory epilepsy screening tool.

And, that REST tool is a very simple form... is a... tool to help recognize these refractory epilepsies-- these cases of people that are just not getting any better... okay... or in control.

And, it has a series of criteria (of questions) that are very easy to answer.

There could be a presentation about that later on in the future. But... the form is so basic that has been implemented in... in ways through the state... as a EMR recognition. It has been implemented as a... just... chart evaluations.

And eventually, what it does... it creates a way of communicating with the physician... when you want to share what you're currently seeing with that resident or that patient or that... loved one of yours.

So, anyway... it's a great opportunity for you to have access to that form.

It is available. The state department has it. And... that... that's actually a perfect example of what would be a perfect for Epidiolex.

Stacy: Excellent... yup!

So, we shared... actually... we shared all of the handouts in... the chat-- so...Tony's... handouts for the resource tools are there.

The REST tool is now in there-- so you should be able to pick it up out of there.. and save those for your use. I'm gonna... to get back here... sharing (just a second). I'm going to pull up the last questions.

Okay. Okay. So, this is where we left. Thank you, John.

Is seizure monitoring without a rescue medication a delegated nursing task?

Now [inaudible] and Google app.

Toni: So...

So, that's really not a question that I can answer-- because this is going to be dependent on your policies and procedures.

So, I don't know if the different... would the different places of residency have different rules or is that... is that mandated by the department of health? Maybe Stacy... I don't...

John: I can elaborate on that question.

It's very important to know, and I can tell you from experience with all my travels, every single state is different of how we care about the I/DD community (right)... and how it comes from the state department.

One thing that cannot be forgotten is... rescue medication is for rescue purposes.

What I mean by that is a lot of states (including the state of California, I just learned recently) are observing that there is an overall usage... too much usage of rescue medications.

So, you have a lot of folks that are having a seizure, and their DSPs or caregivers... the first thing that comes to mind is rescue med.

Okay. Well, those rescue meds come in with side effects or rescue meds are... difficult to administer.

And so, what we lost the sense of is... what can we do to better control those seizures. The rescue med is not going to... help you have or improve (less seizures). It's going to just solve that problem (right at the time). Okay.

So, as a matter of fact, just... so you guys know, the state of California just recently... approved an act... for over-usage of rescue medications in the I/DD facility where now... a certain number (and I need to look at the document), but it clearly says so much number of usage of rescue medications per month... is now considered a misdemeanor.

So, if the state of California is doing that, I predict the state of Colorado will follow.

I predict the state of Oregon and Washington will follow-- because they're seeing how everybody's relying on these medications... just to solve (or put a band-aid), and they're not looking at how to improve the outcome.

So... good question here because... every single state department has their own criteria of how it's being used but one thing in common has been... is that there's way too much over-usage of it-- way too much over-usage of it.

And, that needs to be... that needs to... needs to be controlled some way or the other.

So, hopefully... that will answer some of your questions. It's still great... (a great band-aid), but it is... that's what it is. It's a band-aid.

It's not improving drop seizures. It's not reducing the amount of times you're going to have different seizure types... like the ones Julie and Toni present.

[Background noise]

Participant: Now, I know that... sorry Janelle from Hawaii Behavioral Health.

And, how doctor... you were talking about... it's dependent on our policies and procedures.

And, we send out a lot of our DSPs with the understanding that they're not allowed to administer any medication.

So, in those events where they know that they're not allowed to administer it. However, they are in the community where a seizure occurs.

I think there's some confusion or some misunderstanding about... when that rescue medication, or how or who would be administering it to... (you know)...

John: Yeah...

Janelle: provide... that rescue (you know). So, I think some our DSPs are a little... they're not feeling equipped up there.

Participant: Yeah. and they... they're afraid of liabilities.

Janelle: Yeah... that's...

John: So, usually... you bring that up. Thank you for bringing that up.

Usually, every medication that Julie shared in that slide (that you guys saw there)-- every medication has been approved... (through history... and now the new ones have been approved) by your state board of pharmacy... to be able to be administered within the I/DD space (will be administered period).

So now, it is your agency that you work for, or it is your state department, or it is whoever you are being supervised for to provide that care.

They might have their specific rules of what can and cannot be administered, okay?

So, that is something that you might (if you work for the state)... you might want to consult that with Stacy and her staff... about what kind of rules goes into DSPs administering certain medications and the others. And, it varies... for state. Okay. But, rescue medications, Epidiolex... (everything that was shown in there)... has been approved by the FDA-- which means it has gone through a screening process to make sure that your state board of pharmacy... gives you the okay to be administered. Now, most DSPs are allowed to administer medications in most of the states that I go to.

It could be a little different here.

But, that all depends upon what department wants to do in regards to it. So, and what happens outside of that sitting... you... I mean you should be okay-- because it is.. it's completely approved by the FDA.

So, [hope] that answers your question.

Janelle: Yeah... that [inaudible].

Stacy: Okay. So, I'm going to... we are out of time here. Thank you very much for all of the questions.

I am going to stop on questions here, and get us to our... slide here with our QR code.

Just a second.

Toni: We got these questions in the chat.

Stacy: There are... I'm going to get this up here. Okay.

Alright... so on your screen, if you... have your phone out, you can scan the code there. Let me put into the chat... form.

Okay. And then, the link to the evaluation form is also in the chat.

You can fill out the evaluation form-- request your certificate of attendance there.

We have the zoom... attendance... as well-- so not a problems.

Thank you... yeah. You're welcome. Thank you very much for being here. Thank you for all the comments in the chat. I don't see any questions, but I do see some... very nice comments. I'll make sure that we share those... with the... presenters... and guests.

But, thank you very much... for being here (for your time today).

We hope the information that was shared is helpful, and that you all learned something... or at least gained some... community resources and some resource tools that are useful... to you and... participants that you provide care for.

So, thank you so much for being here. I will leave this screen up for a couple minutes, but you're welcome to... go and have a great rest of your evening. Take care. Thank you!