

## THE NEW WAY TO DESCRIBE YOUR SEIZURE TYPE - (WEBINAR TRANSCRIPT)

- Laura Lubbers: [00:05](#) Welcome everyone to today's webinar. I am Laura Lubbers, and I am the Chief Scientific Officer for Citizens United for Research in Epilepsy, or CURE. Thank you so much for joining us today. CURE is pleased to present our Leaders in Epilepsy Webinars Series, which consists of webinars that highlight some of the key research that's being done in epilepsy.
- Laura Lubbers: [00:26](#) Today's webinar, which is being sponsored by our friends at Sunovion, will focus on the numerous and complicated medical terms that can accompany an epilepsy diagnosis. Knowing and understanding these terms is very important for the management of you or your loved one's epilepsy. This webinar will be presented by Dr. Robert Fisher, who led the International League Against Epilepsy, or the ILAE, seizure classification task force, which came up with new ways to organize and describe seizures and epilepsy types.
- Laura Lubbers: [01:05](#) CURE's mission is to find a cure for epilepsy by promoting and funding patient-focused research. This year, we're celebrating 20 years of impact. Over the last 20 years, CURE has been instrumental in advancing research in many areas, including infantile spasms, posttraumatic epilepsy, sudden unexpected death in epilepsy, or SUDEP, and genetics, just to name a few.
- Laura Lubbers: [01:32](#) Today's webinar is entitled, The New Way to Describe Your Seizure Type, and we'll discuss the new ways to organize and describe seizures and epilepsy types according to the ILAE classification system. You'll also learn about the differences between seizure types, types of epilepsy and epilepsy syndromes, as well as what clinical features help create this new classification system.
- Laura Lubbers: [01:59](#) Dr. Robert Fisher is the Moslah Saul MD Professor and Director of the Stanford Epilepsy Center and EEG Lab. He's published nearly 220 peer-reviewed articles, and three books. He's received numerous national and international awards for his work, including his

teaching, and he's a past President of the American Epilepsy Society.

- Laura Lubbers: [02:22](#) He's been involved in clinical trials and deep brain stimulation for epilepsy and on the next generation biggest nerve stimulation devices. Before Dr. Fisher begins, I'd like to encourage everyone to ask questions. You can submit your questions anytime during the presentation by typing them into the questions tab on the GoToWebinar control panel, and then clicking send. My colleague from CURE, Brandon Laughlin, will read them aloud during the Q&A portion of the webinar.
- Laura Lubbers: [02:54](#) We do want this webinar to be as interactive and informative as possible. But to respect everyone's privacy, we ask that you make your questions general and not specific to a loved one's epilepsy. I also want to mention that today's webinar, as well as all previous and future webinars, will be recorded and are available on the CURE website.
- Laura Lubbers: [03:14](#) So with that, I'd like to turn it over to Dr. Fisher.
- Robert Fisher: [03:19](#) Thank you very much. Thanks to the audience for joining us today. We're going to talk about what your seizures are called and why it matters. These are some famous people with seizures. We're really not sure that all of them had seizures. Some of them, for example, just repeatedly fell off a horse hundreds of years ago, but probably, most of them had seizures and some had epilepsy.
- Robert Fisher: [03:45](#) Perhaps in another talk, we could spend the entire session talking about the interesting stories of these individuals, but I just wanted to point out that some people have seizures and some people have epilepsy. Now, what's the difference between those two?
- Robert Fisher: [04:00](#) Well, a seizure is the event. It's an electrical storm in the brain, hyper-synchronization of your brain cells firing together in an abnormal pattern, whereas epilepsy is the condition of seizures that spontaneously come back on their own, spontaneously recurrent seizures. Therefore, you can have epilepsy, for example with the febrile seizure,

one of the most common causes of seizures in the world, and not have epilepsy because it's not spontaneous, it's provoked by the fever, or traditionally, you could have a single seizure and that was not epilepsy.

Robert Fisher: [04:44](#) But now, the definition of epilepsy has changed. How has it changed? First, the old definition. Epilepsy is a disorder characterized by two or more unprovoked seizures occurring more than 24 hours apart. So you had to have two seizures to have epilepsy. That is a concise and easy-to-apply definitions, which doctors like, but it unfortunately has some problems.

Robert Fisher: [05:10](#) One problem is you can never outgrow epilepsy. You can have an unprovoked seizure when you're two, another when you're three. And now, you're 80 years old, would never another seizure, not on meds, you still have epilepsy. Who wants that? No one. The other problem is that in the other direction, sometimes, a doctor knows when a person comes in after one seizure, that it's very likely that there are going to be more seizures.

Robert Fisher: [05:36](#) For example, maybe you have some kind of problem on your MRI that looks like it's going to cause other seizures, or your EEG. So the new definition accounts for that. And then some people can have an epilepsy syndrome like Benign Rolandic Epilepsy, which is called benign epilepsy with centro-temporal spikes. And they may only have one seizure, but they have other clinical features that make them known to have that epilepsy syndrome, and yet, they don't have epilepsy until they have a second seizure. It's silly to have a syndrome and not have epilepsy.

Robert Fisher: [06:13](#) And then some who have seizures that are triggered by particular stimuli like photic stimulation, they are provoked, but the brain response is abnormal. And we've been treating those people as if they have epilepsy, even though the old definition didn't apply.

Robert Fisher: [06:29](#) So with all of these things, we've cleared out the dustbin of the old definition and upgraded it so that it's more like what clinicians really think of as who has epilepsy, published it in *Epilepsia*, which is the journal of the International League Against Epilepsy. And

now, epilepsy incorporates the old definitions, the only if you have two unprovoked seizures, but you also can have one seizure and a high chance of having another if you're known to, if your doctor knows that, if the information is there, then you can have epilepsy after one seizure.

Robert Fisher: [07:04](#) If you have an epilepsy syndrome, you have epilepsy. And perhaps most important, epilepsy is now officially considered resolved for individuals who had an age-dependent epilepsy syndrome and outgrew the age, or those who have remained seizure-free for the past 10 years, off seizure medicines for the last five.

Robert Fisher: [07:25](#) In those circumstances, it's not guaranteed that you're going to be seizure-free, but you probably will. And if you're filling out a form, for example, that asks, "Do you have epilepsy?" At that point, you would be given some backing to be able to say, "No, the epilepsy is gone. It's resolved." Possible consequences of this are both good and bad. One is it's closer to the view of how clinicians really think of people in diagnosing them.

Robert Fisher: [07:54](#) It may help reimbursement, it gives support for an earlier diagnosis and therefore, might encourage what we call disease-modifying therapy to prevent the development of epilepsy, although we're not very good at that yet, at least, this will encourage it, and it allows for outgrowing epilepsy. However, it may upset those who were diagnosed sooner, increased stigma, apply some labels that could restrict activities earlier.

Robert Fisher: [08:20](#) We talk about data on recurrence after a single seizure, but often, that's very limited in the scientific literature. And when we don't know, we just fall back on the two seizure definition of old, and it makes diagnosis more complicated for the doctor. So it has both good and bad consequences.

Robert Fisher: [08:42](#) So now, we come to part two. Part one was definition, part two is classification. What type of seizure is there? We had been using a classification that goes back to 1981, and it was pretty good, but it had some problems that I'll get to in a minute. So the ILAE decided to upgrade this classification just as they

did the definition, and I participated in that task force as well.

Robert Fisher: [09:16](#) So we renamed the seizures. I had to go into the witness protection program for a while after changing the names because doctors, and I think patients, don't like changing anything that they've gotten used to. But by and large, its value has been recognized, it's gotten accepted, it's starting to be in use since its introduction last year and I've been able to come out of the witness protection program. So here I am.

Robert Fisher: [09:44](#) Why is classification important? Why do we bother doing this at all? Well first, it's a common language for doctors and others to communicate. When we're talking about you or writing in the chart, the seizure type may guide what kind of testing is needed. You might need an MRI for most seizure types, but not for a few of them.

Robert Fisher: [10:03](#) Certain drugs work better for some seizure types, and some seizure types can be helped by surgery or neurostimulation, and others can't. And it's a big help to epilepsy research to have accurate seizure types as we do the research. This is the old classification with the old terms. It used to be partial seizures, that's changed to focal now.

Robert Fisher: [10:29](#) You may know simple partial seizures, which is no loss of consciousness or memory. There are different subtypes, or complex partial seizures, which are seizures with loss of memory or confusion. Then there are a variety of different types of generalized seizures, and many seizures can't be classified especially if you don't know the onset.

Robert Fisher: [10:51](#) So what are the problems with this classification? Some seizure types can have either a focal or a generalized onset. And that makes a big difference because if you have a focal seizure onset, we really want to know, is there something going on in your MRI of that focal part of your brain? Whereas, with generalized onset seizures, they're usually a neurochemical or a transmitter ion channel in your brain cells, something potentially genetic that's behind the cause of the epilepsy.

- Robert Fisher: [11:27](#) And we don't actually see anything wrong when we look at the brain structure. Lack of knowledge about the onset in the old classification made a seizure unclassifiable. Assessment of consciousness could be very difficult especially after the fact. And there were some terms in the old classification that didn't have a high level of acceptance or understanding.
- Robert Fisher: [11:49](#) Psychic seizures, partial seizures, simple partial, complex partial, just cognitive seizures. What do those terms mean? Really not obvious without explanation. And then some important seizure types were not included. So there's the new classification. It was developed in 2016, but it was published in 2017. We still divide seizures into focal onset in one hemisphere of the brain or less, or generalized onset, which looks like it appears in both hemispheres of the brain at about the same time, according to your physical symptoms or if an EEG is running. We see EEG activity on both sides of the brain at the start at once.
- Robert Fisher: [12:35](#) We think these generalized seizures occur from deep pacemaker areas that fan out to both sides at once, or networks of the brain that synchronize so quickly that we can't see where they start. It makes a difference because focal onset seizures, the drugs, surgery possibilities, the workup that we do for what's going on in the place where seizures start are all different than they would be if you had a generalized onset seizure.
- Robert Fisher: [13:03](#) Now, the focal onset seizures are divided into the motor and the non-motor categories, and we make special attention to awareness with these, and I'll come back to why in a few minutes. Any seizure that starts at one place of the brain can spread to the whole brain making a bilateral tonic-clonic seizure, what you probably think of as grand mal seizures.
- Robert Fisher: [13:26](#) So generalized onset seizures have a variety of motor movement types and absence seizures, for which the very old term, is a petit mal seizure, which is just staring and fumbling. Then you can have seizures of unknown onset, which now can be at least partially classified so we know what we're talking about as a term for them until maybe more information becomes

known to let us know if it had a focal or a generalized onset.

Robert Fisher: [13:54](#) This is the basic classification. The more detailed classification is here, and I will not go into it because we don't have time for it, except to point out that it's the same classification that you just saw before with a bold. However, the smaller fonts give greater detail for say, a neurologist who wants to make a finer detail of classification.

Robert Fisher: [14:22](#) So how is this different? Well, let's look at the old term and the new term. Unconsciousness is very important in seizures, so whether you pass out or not makes a big practical difference to what happens and what you can do, but it's hard to evaluate. So we use impaired awareness as a surrogate marker of consciousness when we talk about focal aware or focal impaired awareness seizures.

Robert Fisher: [14:49](#) Basically, you have an impaired awareness seizure if you're not remembering or not knowing what's going on during the seizure. Partial seizure is now called focal seizure. A simple partial seizure with no loss of consciousness or awareness is now a focal aware seizure, whereas a complex partial seizure is a focal impaired awareness seizure. Just cognitive, you don't use anymore for seizure classifications.

Robert Fisher: [15:16](#) Psychic, which sounded a little like witchcraft to me always, now is a cognitive seizure. And secondarily generalized tonic-clonic is a focal to bilateral tonic-clonic seizure. Then you can also have behavior arrest seizures where you just freeze up.

Some seizure types can be either focal or generalized, including atonic, which means going limp, clonic, which means rhythmical jerking like this, epileptic spasms, which is in children with these kinds of sudden seizures.

Robert Fisher: [15:52](#) Myoclonic is irregular twitching like that as opposed to the regular twitching of clonic seizures. Clonic seizures are stiffening, and tonic-clonic is a stiffening followed by the clonic rhythmical jerking. So with the possible exception of tonic-clonic seizures, these can all start either focally, or in a generalized fashion.

- Robert Fisher: [16:23](#) Hypothetical case, you hear a noise, you enter the video-EEG room to find the patient in bed, grunting, eyes rolled up, all limbs stiff, before you entered the patient's bedroom. Then rhythmically jerking for a minute. He was off-camera at the start. What seizure type is this? In the old classification, it was unclassified, even though it's clearly some type of tonic stiffening and clonic jerking seizure. So now, we can define it as tonic-clonic even if the onset is unknown.
- Robert Fisher: [16:53](#) I mentioned that consciousness has a key role among many possible behaviors in seizures. It's always been key because it's important for driving, it's important for safety, it's important for employability, it's important for interfering with your school and learning. So an impaired consciousness seizure is a synonym for impaired awareness. This is the result of one impaired awareness seizure on the road. Not a good idea.
- Robert Fisher: [17:25](#) So when doctors are classifying seizures, or when you're classifying your own, you have to decide whether the seizure onset is starting on one part of the body, like with tingling in a hand or twitching or whether it's generalized. Sometimes, the focal onset may just be a thought or a feeling like a déjà vu. Your generalized seizures typically don't have any warning leading into them. A warning being called an aura, but it itself, an aura, is a small seizure.
- Robert Fisher: [17:57](#) Then you decide whether awareness is impaired. And if awareness is impaired at any point during the seizure, then it's a focal impaired awareness seizure, or a generalized seizure. We don't talk about impaired awareness in the generalized onset seizure categories because with some exceptions, and they're few. Awareness is always impaired during a generalized onset seizure.
- Robert Fisher: [18:22](#) So aside from awareness, which can classify a seizure if it happens at any point, all the other seizure types are classified by what happens first. So if you have a tingling in your hand, that is a focal aware sensory seizure. Even if later, you go to stiffening and jerking, why do we do it that way? Why do we classify it by the first rather than the most prominent?



- Robert Fisher: [18:48](#) The reason is because the place where the seizure starts generates the first signs or symptoms, and we're very interested as neurologists in knowing where does the seizure start in your brain? As it spreads, what we call propagates, it can bring in many other symptoms, but the seizures are named, by what happens at the start. And then seizures can be further subclassified by motor and non-motor findings.
- Robert Fisher: [19:17](#) So the net effect of updating the classification should be, it should make the choice of a seizure type easier, procedures that didn't fit into any prior category, particularly those that were just named for generalized seizures, but could also occur focally at the start. It clarifies what is meant when a seizure is said to be of a particular type, and it should provide more transparency of terminology to the nonmedical community.
- Robert Fisher: [19:45](#) I'm not sure that people ever really knew what a complex partial seizure was. Does that mean it was complicated? No. And a simple partial seizure could almost be offensive if people thought it meant the seizures were simple because the consequences of those seizures on your life may be far from simple.
- Robert Fisher: [20:06](#) So in conclusion, the definition of epilepsy has broadened to allow two unprovoked seizures, the old definition, or the new thing, one seizure with a high chance for having another. Epilepsy can be resolved after 10 years, seizure-free, if you've been off seizure medicines for the last five years. The seizure classification has also changed, your new focal and generalized seizure types. And the most important because it's so common are the focal aware and the focal impaired awareness seizures, previously called, simple and complex partial.
- Robert Fisher: [20:42](#) We would have loved in the task force to create a classification of seizure types that was based on the scientific reason that there are different seizure types in the brain, but we're just not there yet in terms of scientific understanding. So this new classification is really a tweaking, a modification of our observational old classification.

- Robert Fisher: [21:04](#) As Eliza Doolittle says, "Words, words, words. I'm so sick of words." That has been expressed to me, but I think you'll find over time, this is a better way to name your seizures. And the last slide that I have is a slide on how you can help declassify your own seizures. First, carefully record the sequence of what happens during a seizure, especially at the start because that marks the seizure focus.
- Robert Fisher: [21:31](#) Report whether you lose awareness or become forgetful during a seizure. Family may need to tell you what you do during a seizure because seizures can produce a memory wipe and you may not know exactly what you're doing, or how impaired you are. Clarify if there were different types of seizures, big ones, small ones. You may have more than one type of seizure, or one type may go to another.
- Robert Fisher: [21:55](#) It's okay to use your own name for your own seizures if you're consistent and your doctors will be able to take your name, for example, a lip trembling seizure and ask you some other questions and then map that to the official name. And soon, more educational material and even a software application that I'm writing that will walk you through how to classify your seizures will be available.
- Robert Fisher: [22:19](#) So that is the end of my talk, and we can now proceed to questions.
- Laura Lubbers: [22:26](#) Thank you so much. Thank you so much, Dr. Fisher. That was really interesting and really got me thinking about our understanding of epilepsy and how far it's come because of the research and the classifications that we need to use. So thank you for that.
- Laura Lubbers: [22:40](#) We will now go to the Q&A portion of the session. And again, if you have a question, please do type it into the GoToMeeting webinar panel and Brandon can go ahead and read that aloud.
- Robert Fisher: [22:56](#) And I will apologize in advance, I won't be able to diagnose or treat you or your family members over the web because we, doctors, feel strongly that we need to examine people. We need to take the whole history. And hopefully, not in such a public forum. So this will be like being a radio doctor. And try to keep

your questions general and I'll try to keep my answers general.

Laura Lubbers: [23:24](#)

Thank you.

Brandon L.: [23:26](#)

Great, thank you. So the first question actually is a good summary question, and that is, why is this new classification system important to me?

Robert Fisher: [23:43](#)

Sure. So how does it matter to you? Well, perhaps the most obvious thing is over the many years of working with people with epilepsy, I have found out that there's a great desire for them to know what their seizure types are called. And the studies that have looked at the correspondence between what people with epilepsy think their seizures are called, and what their doctor thinks their seizures are called, show that there's often not a very good correspondence.

Robert Fisher: [24:15](#)

And I'm not implying that the people with epilepsy are wrong because often, the doctors are not really very accurate about what the seizure type is. And when I see that circumstance, it just means that the names are too complicated. So this is a streamlining. It should help you communicate to others, to others like you, if you go on websites and want to share common experiences and to your medical team of what type of seizures you really have.

Robert Fisher: [24:45](#)

Secondly, it's going to be useful for people whose seizure types just didn't exist in the previous classification. We can never classify every seizure type, but now, it includes more than it did before.

Brandon L.: [25:05](#)

Great. Thank you. So next question, we got some questions obviously about specific seizure types. And someone asked if there's a definition or a description for autonomic seizures. And if so, what would that be called, and what would be the most common characteristics of that seizure type?

Robert Fisher: [25:26](#)

Good question. What it's called is focal autonomic seizures. It could be focal aware autonomic or focal impaired awareness autonomic seizures. The autonomic nervous system is your sympathetic and your parasympathetic system. Sympathetic is your fight-or-flight system. It involves sweating, hair on your

arms rising up on end, pupil dilation, increased heart rate.

- Robert Fisher: [25:55](#) Parasympathetic is your more internal system, like your digestive processes, slowing the heart rate down, slowing the breathing and the pupil constriction. So if you have seizures that play into the brain structures that control the sympathetic or the parasympathetic system, you may get heart racing, you may get gastrointestinal symptoms, you may get a sense of heat flushing, hair rising. These are autonomic symptoms.
- Robert Fisher: [26:29](#) And if that's the first thing that you have, then you have a focal autonomic seizure.
- Brandon L.: [26:38](#) Great. Thank you. The next question actually came through in a variety of forms, but we did get this asked quite a few times, and that is, can a person actually have more than one type of seizure?
- Robert Fisher: [26:55](#) Absolutely. You can have more than one type of seizure. And there really are two different baskets that I would put that in to. One is you have one seizure focus, which is you have one place in your brain where seizure starts. But sometimes, the abnormal electricity stays in one place. Other times, it spreads a bit farther, other times, it spreads a bit farther than that.
- Robert Fisher: [27:24](#) So for example, you might have a focal aware seizure let's say with a sense of déjà vu, strange familiarity. That may be all that happens in some seizure, and then you might call it an aura, which is an old term for a small seizure that could lead into a larger seizure. So if the abnormal electricity then spreads to both sides of the brain, then you're not going to be able to lay down and remember memory traces.
- Robert Fisher: [27:53](#) So now, you've got a focal aware seizure, which has progressed to a focal impaired awareness seizure. And then if the activity spreads to the whole brain, then you'll completely lose consciousness. You'll fall, you'll stiffen, tonic activity, you'll shake and you have a focal to bilateral tonic-clonic seizure. So in a way, although we name it three different seizure types, it's really one seizure starting place that's three different

seizure types because it may spread to different extents.

Robert Fisher: [28:28](#) And by the way, seizure medications may keep it from spreading and may turn focal to bilateral tonic-clonic seizures into just focal aware seizures, and that would be a good thing. So the second basket is where you really have two completely different seizure types that don't overlap. That's much less common than the first thing that I said.

Robert Fisher: [28:50](#) But you might have a focal seizure that causes hand tingling, a focal sensory seizure, and then you may have a different place in the brain that gives rise to seizures, which might be a focal tonic seizure that causes stiffening of the right arm, and one might happen sometime and one might happen another time. So yes, you can have more than one seizure type. And some people unfortunately have lots of different seizure types.

Brandon L.: [29:22](#) Thank you. Dr. Fisher. The next question actually came through in a variety of fashions as well and obviously is of importance to many people. And that is, is it still okay to use a lot of these considered old terminology such as grand mal and petit mal and terms of that nature?

Robert Fisher: [29:43](#) I've worked very hard not to be the terminology police. And in fact, a year down the road, which we are in this classification, when I read my clinic notes, I'm still going to the extra trouble of using the old terms and the new terms every time I classify a seizure in writing, putting one of them in parentheses. So I might say, see, there are several generations of this. It's not just a new an old classification because if we go back to the '50s, the terms that people were using were petit mal, grand mal and psychomotor seizure, and sometimes, focal motor seizures.

Robert Fisher: [30:24](#) Also not that bad. I think we've improved it a little, but those were not that bad. And then in 1981, we started having the simple partial, the complex partial, the secondarily generalized and so on. So if you're enamored of an old term, then you can use it, but here's the thing that causes confusion. A lot of my patients talk about petit mal and grand mal seizures

when they're all in effect, focal impaired awareness seizures.

- Robert Fisher: [30:57](#) And the petit mals might be the smaller ones that aren't as intense. The grand mal, they say are the ones where they have a feeling of dread or doom or something else that makes them stronger. So that becomes confusing. If you're using an old term, but it isn't actually the right term for your seizure type, then that's not so good because that may mislead you in your conversations with people who have other seizure types when you're trying to compare experiences, or it may even mislead some doctors.
- Robert Fisher: [31:35](#) But otherwise, no, I'm not opposed to using the old terms if you do so correctly and consistently.
- Brandon L.: [31:45](#) Great. Thank you. The next question is a good question that came from one of the audience members. How often is jerking associated with a loss of consciousness and impaired awareness?
- Robert Fisher: [31:59](#) Probably, the majority of the time. You can have focal clonic seizures with jerking, or focal myoclonic. Remember, myoclonic is irregular twitching, whereas clonic is rhythmical, sustained jerking. It looks like this. So if it just stays in the motor center, you're not going to have loss of consciousness or loss of awareness as a marker of consciousness, but if it spreads to both sides of the brain, then you're probably going to have loss of consciousness.
- Robert Fisher: [32:31](#) So if a person tells me that they're having jerking of their entire body, but they're awake, aware, alert, remembering, they see they're jerking, they report it to me afterwards, then I'm wondering, was this really an epileptic seizure, or was it one of the imitators of the epileptic seizures, because generalized jerking should not be associated with loss of consciousness?
- Robert Fisher: [32:56](#) Now, let me make one exception to that, and I apologize for being complicated, but it's just the way things are. Some seizures, even when generalized, are so brief that you can't even tell if someone lost consciousness. And the classic example of that are generalized myoclonic seizures. It may look like this,

and I realize you're only seeing my hands or my head, but the legs might be jerking too. It might look like this.

- Robert Fisher: [33:22](#) That could be a generalized myoclonic seizure. We could see spikes on the EBG going with that, and it would be impossible to tell whether the person lost consciousness. Another type where that may occur, and this one I won't imitate because I might hurt myself, would be a generalized atonic seizure where you suddenly go limp and you drop to the ground.
- Robert Fisher: [33:41](#) But virtually, as soon as you hit the ground, the seizure is over and you're awake and alert. That one too, we might not be able to measure consciousness. Sorry for the long answer.
- Brandon L.: [33:53](#) No, that's great. Thank you. The next question is actually more of a clarification question. And someone asked if you can clarify if tonic-clonic seizures are exclusively generalized.
- Robert Fisher: [34:07](#) Yes. Generalized. Tonic-clonic seizures are generalized. But there was a seizure type that is called focal to bilateral tonic-clonic, and those are not exclusively generalized. So you can have both varieties. I suppose I should have said no at the beginning because of that. The reason I said yes is because there is no defined seizure type of focal tonic-clonic seizures. It does exist if you look hard in the literature, but it's so rare that we decided not to put it in the classification.
- Robert Fisher: [34:47](#) Now, what's the practical import of this? If you have a tonic-clonic seizure, tonic stiffening, clonic jerking, your doctor really should look hard and talk to you hard about whether you have a focal aura, whether you have an onset, a warning to that because that means it's a focal to bilateral tonic-clonic seizure, and we ought to pay attention to what's wrong with that focal part of your brain where the seizure starts.
- Brandon L.: [35:15](#) Great. Thank you. The next question is actually someone asked if there is a definition of cluster seizures, and if so, what are the parameters?
- Robert Fisher: [35:27](#) Okay, that's a good question. Cluster seizures mean seizures that come together in time. And it implies

that if you have one seizure, you're pretty sure you're going to have another one in a fairly short order. We haven't been able to agree on exactly what time parameters those are because you can imagine the variability.

Robert Fisher: [35:47](#) If a person has only one seizure a year, then having three seizures in a month might be a cluster for them. But someone who has seizures every day might require having a whole bunch of seizures together in one day in order to call it a cluster. So you have to relate the cluster to how frequent the seizures are normally.

Robert Fisher: [36:10](#) We do care about clusters, and there are medications that are being tested now to spray in the nose or to inhale to disrupt clusters of seizures. And I think many of you probably carry medicines like lorazepam, or equivalent, around in your purse or your pocket so that you can take it after one seizure if you have clusters in order to use it as a cluster buster.

Robert Fisher: [36:40](#) There's also the marketed rectal diazepam medicine that can be used to break up clusters of seizures. And that's approved and it's been used for many years.

Brandon L.: [36:55](#) Thank you. The next question, what new ways are there to differentiate between a dystonic storm and a seizure? And how do treatments vary if somebody has a dual diagnosis?

Robert Fisher: [37:10](#) I didn't catch the phrase. To differentiate between a what storm?

Brandon L.: [37:16](#) Dystonic storm.

Robert Fisher: [37:17](#) Oh, dystonic storm. Okay. So dystonia means a sustained abnormal posture. So it could look like this. And dystonia can be a symptom of seizures when the seizures spread to the basal ganglia and the motor centers of the brain. So often, in a focal impaired awareness seizure, you may see progression to some dystonic posturing as part of a seizure.

Robert Fisher: [37:49](#) But the confusing part is dystonia can also exist when it's not a seizure, when it's a movement disorder, hereditary dystonia or a side effect of medications



and so on, and it can be a hard distinction. Sometimes, you can't really tell when you're just looking or talking to the person. But if they're losing awareness, then you know it's a seizure because loss of awareness is not part of movement disorder dystonia. If it spreads from dystonia to a tonic-clonic seizure at any point in your history, then that's a seizure. That's not dystonia.

- Robert Fisher: [38:24](#) Sometimes, it requires a video-EEG, recording the brainwave activity during the attack to tell because a seizure will show the electrical storm in the brain and the movement disorder dystonia will not. So that's one to consult a team that's got some expertise both in epilepsy and movement disorders to make a distinction.
- Brandon L.: [38:48](#) Great. Thank you. Just a few more questions here. If a seizure does have a focal component, but doesn't necessarily visibly start with a clear focus, does that have a definition, or is that called something specific?
- Robert Fisher: [39:04](#) We sometimes talk about cryptic or hidden onset of seizures, and we do worry about that. For that reason, as we're learning to use the new classification, some of my colleagues have argued that unless we're very sure that a seizure has a generalized onset, good observation of the behavior, good history, probably even an EEG during the type of seizure, we should classify it as unknown onset until we're sure because it may matter if you're entering a drug trial for generalized onset seizures or using certain medicines or whether you're going to have a possible workup for focal seizure surgery.
- Robert Fisher: [39:50](#) So we do concern ourselves a lot with seizures that seem to be generalized from onset, but in fact, they're starting in a silent or cryptic or hidden focal area of the brain. We don't have a special name for that seizure type.
- Brandon L.: [40:08](#) Great. Thank you Dr. Fisher. The next question, are certain classifications of seizure onset at a higher risk for SUDEP?
- Robert Fisher: [40:18](#) Yes. Generalized tonic-clonic seizures, especially frequent ones unfortunately.

- Brandon L.: [40:27](#) Great. Thank you. The next question actually deals with syndromes. When someone with a specific epilepsy syndrome, or in this example, they used Doose Syndrome have a specific seizure classification?
- Robert Fisher: [40:43](#) So I didn't talk much about syndromes or the classification of the types of epilepsy just because of reasons of time limit. But an epilepsy syndrome puts together a lot of different features. It puts together the types of seizures that you have, maybe absence seizures, the old petit mal, but you may also have generalized tonic-clonic seizures, the old grand mal.
- Robert Fisher: [41:10](#) You may have a constellation of seizure types together with your clinical picture. Is your neurological exam normal with your EEG picture? Is it showing epileptic activity in the brain, and what type with your brain imaging with a lot of laboratory tests with genetic history and with prognosis? So it's like the whole picture. Epilepsy syndromes are extremely important because that's what doctors really deal with more than just the seizures in isolation.
- Robert Fisher: [41:44](#) That's what determines prognosis, that's what determines what type of treatment we use. And the seizures are just the first component of that, are the building block of determining the type of syndrome and the type of epilepsy that you have. So they're not the same thing, but seizures are a very important piece of information to determine the epilepsy, yes, syndrome.
- Robert Fisher: [42:08](#) Syndromes are things like Lennox-Gastaut Syndrome, Dravet Syndrome, childhood absence, juvenile absence epilepsy, juvenile myoclonic epilepsy, those are all epilepsy syndromes. Infantile spasms are both a seizure type, and West Syndrome is a syndrome of having infantile spasms.
- Brandon L.: [42:35](#) Great. Earlier you mentioned the outgrowing of your epilepsy. Now, how would a neurologist determine if you have outgrown epilepsy if you're currently on a daily medication?
- Robert Fisher: [42:48](#) You can't tell if you've outgrown your epilepsy unless you're off medicines. Now by saying that, I am not

encouraging anybody to stop their medicines to see if they're off epilepsy. We all have ways of safely trying to see if people can get off medications or are suitable for getting off medications. So please do not just stop your epilepsy medication to see if you need it.

Robert Fisher: [43:16](#) But the neurologist will determine whether there have been seizures recently in recent years. And sometimes, people aren't even aware that certain types of daydreaming or fumbling or automatic activity may in fact be seizures. And if those exist, you certainly don't want to stop medication. So it needs a careful history. Probably, it would need an EEG to see if there's any epilepsy-like activity showing up in the EEG patterns.

Robert Fisher: [43:46](#) You have to determine whether a person is willing to take a risk of having a seizure by withdrawing the medications. And then I personally ask people not to drive for a period of time because we don't want to find out that the medicines were needed while the person is on the highway, and that is often a deal breaker for stopping medications.

Robert Fisher: [44:06](#) But you cannot claim that your epilepsy is resolved so long as you are still taking seizure medicines since you don't know what would happen if you stop.

Brandon L.: [44:19](#) Great. Thank you. We got about three more questions here. This one is more of a clarification question. Is petit mal the exact same thing as what is now called an absence seizure?

Robert Fisher: [44:29](#) Yes.

Brandon L.: [44:33](#) Great. Thank you. And the next question actually is about the actual terms. And for people living in the U.S. who don't actually speak English as their primary language, have these terms, do you know, have they been translated into other languages?

Robert Fisher: [44:50](#) The I in ILAE is international. The committee was, I think, 19 people, and all of them spoke English, but most of them were not from the United States. So there was a very heavy representation of other languages. And the terms have been translated into

many other languages. We paid attention to how the terms would be in other languages.

- Robert Fisher: [45:22](#) It's interesting that it turns out that the words, consciousness and awareness are actually the same in many other languages so there was some mystification about why we were using one word to substitute for another when they were the same. But I think we've mostly got the terminology okay in multiple different languages.
- Brandon L.: [45:45](#) And then our final question, actually the good wrap-up question, and that is, to your knowledge, obviously, are the new classifications being commonly used by doctors now?
- Robert Fisher: [46:03](#) Not yet. There's a diffusion timeline here. They're starting to come in. When you write a journal article now in epilepsy, the editors require that the new terms be used so doctors will be reading articles using the new term with familiarity. Those of us who were involved in the reclassification give a lot of talks to a lot of different groups.
- Robert Fisher: [46:34](#) I think that insurance companies will probably start using the new terminology pretty soon. And then there's an international classification of diseases called the ICD, which always lags behind the specialty organizations in naming things, but new versions of ICD, the next version that's being written now is ICD-12, which won't be out for a few years, will incorporate the new terminologies.
- Robert Fisher: [47:04](#) So it's slowly coming into play, but I don't think we'll ever see the end of grand mal, petit mal in the oldest terminology.
- Brandon L.: [47:20](#) Great. Thank you Dr. Fisher. Laura, I'll turn it back over to you.
- Laura Lubbers: [47:25](#) Thank you, and my thanks to you as well, Dr. Fisher. I thought that was a really insightful presentation. It really helps us to understand the terminology and the questions. I want to do a shout-out to our audience, what wonderful questions, and I really think working through all of those questions have really helped us

understand even further how to use the classification system.

Laura Lubbers: [47:48](#) So thank you so much.

Robert Fisher: [47:51](#) I think they were great questions.

Laura Lubbers: [47:52](#) Yeah. Yeah. So if you do have any more questions about this topic, or any of CURE's research programs, please do visit our website at [cureepilepsy.org](http://cureepilepsy.org), or you can email us at [info@cureepilepsy.org](mailto:info@cureepilepsy.org). Again, I want to thank you for joining us today. It was a great audience, great presentation.

Laura Lubbers: [48:12](#) Our next webinar will be on a topic of CBD, where we have a lot of people who are interested in learning more about cannabidiol and CBD. So that presentation will be on October 24th at 1:00 P.M. Eastern Time, and it will be presented by Dr. Anup Patel, from the Nationwide Children's Hospital in Columbus, Ohio.

Laura Lubbers: [48:34](#) So we look forward to having you join us then. And again, many thanks to Dr. Fisher for his time and expertise.

Robert Fisher: [48:41](#) Thanks for inviting me.