

Seizing Life, episode 35
New Emergency Meds to the Rescue - Transcript
Dr. Linda Laux

- Kelly Cervantes: [00:00](#) Hi, I'm Kelly Cervantes, and this is Seizing Life, a weekly podcast produced by Citizens United for Research and Epilepsy, CURE.
- Kelly Cervantes: [00:18](#) Today I'm delighted to welcome Dr. Linda Laux to the podcast. Dr. Laux is the medical director of the Comprehensive Epilepsy Center at Ann and Robert H Lurie Children's Hospital of Chicago. She's also an associate professor of pediatrics at Northwestern University's Feinberg School of Medicine. Dr. Laux has over 25 years of experience in neurology with a focus on child neurology. She's here today to discuss rescue plans and rescue medications and provide background on two new rescue drugs that have recently come on the market.
- Kelly Cervantes: [00:49](#) Dr. Laux, thank you so much for joining us today. I know you are an incredibly busy doctor, but this is such an incredible topic that is so important to patients and their families. So let's get into those rescue medications. The seizure isn't stopping, and additional interventions need to be taken. What are the rescue meds that have been available? And there's a couple new ones on the market, and we'll get to those in a minute. But for the last 20 or so years we've had the same meds with nothing new until recently. What were those meds and how did they work and which seizure types were they predominantly used for?
- Dr. Linda Laux: [01:40](#) So the medication that's been FDA approved since 1997 is rectal diazepam or brand named Diastat. And that was the first medicine that you can give to somebody actively seizing, which it's then not possible for them to really take an oral medicine in the midst of, especially a grand mal seizure or generalized tonic clonic seizure. So this was a medicine that is given by a syringe in the bottom. So it's a rectal delivery system of the medication that gets absorbed through the mucosa straight into the bloodstream, so it's pretty fast-acting and hopefully would be able to stop the seizure, so prevent it from becoming a seizure emergency.
- Kelly Cervantes: [02:27](#) The delivery system makes sense given that if you are having a seizure, you are not able to take a med orally. However, outside of delivering that type of medicine to a young child, that can be incredibly awkward for an adult or for a child who is in school and you're going to ask the teacher to deliver that med in the classroom. Not exactly. I know that that has been a major problem for patients for years, that this is a very awkward and uncomfortable way to have to receive this medication. That said, I also know from personal experience that there are other

meds that have been used as rescue medications in an off-label sort of way. What are those meds and how do they differ?

Dr. Linda Laux: [03:24](#)

The medications that are used as rescue medications are in the category of what we call benzodiazepines. It is a class of medications that acts on the GABA or inhibitory system of the brain to try to then stop the seizure. If any of us were to go into an ED actively seizing, we would get one form or another of these benzodiazepines, of which the rectal diazepam is one of them.

Dr. Linda Laux: [03:51](#)

The other medicines that we have used off-label are in that same class of benzodiazepines. We know they work because they're usually given in an IV formulation for somebody who has a very, very prolonged seizure in the hospital, but obviously a family or a person cannot do that at home. For the children I take care of, even before these newer rescue medicines have been FDA approved, which we'll talk about, we were using an IV formulation of midazolam, and it would simply be the family would either get prefilled syringes or they would get a vial of the medicine and they would have to draw up the medicine in a syringe. You then put what's called an atomizing cap on top of the syringe. It changes liquids to aerosols, and you would go ahead and spray it in the nose. That was one of the more common of the not FDA approved route to give an FDA approved medicine.

Dr. Linda Laux: [04:55](#)

Some people have also used some of these medicines, and Midazolam is the one I've seen most commonly, as a buccal route, buccal meaning between the cheek and the gum. Remember, the child's lying on the side in the midst of a seizure. They would just put the syringe in the corner of the mouth between those two areas. One other would be an intramuscular form, so somebody giving the medication actually into the muscle, because again, they're just quick routes. What you want for home use is something that's quick that can be given by the family or parent at school and is safe.

Kelly Cervantes: [05:32](#)

Absolutely, and I do also want to note that these are not necessarily straightforward solutions and that you do have to really figure out the right med for the patient just as you do for any daily medications that are being taken. So now we have a couple new medications that have recently been FDA approved, and I really think that this is going to change lives. These are not cures, but they are treatments, and the more options we have the better. Please tell us about these new drugs that are now available.

Dr. Linda Laux:	<u>06:13</u>	The first is one that you can now get in the pharmacy. It is called Nayzilam. It is an intranasal Midazolam. I have an example here to show you what it looks like and how you would use it.
Kelly Cervantes:	<u>06:25</u>	I'd love to see that.
Dr. Linda Laux:	<u>06:26</u>	It is FDA approved for patients 12 years of age and older, so it will be huge for those patients, teenagers, young adults, school, work, out and about to be able to have this medicine on you to stop a prolonged seizure or stop repetitive seizures. It's going to change their days because they'll be able to get out and live their lives to the fullest. This is what it looks like in terms of just the box. This is a training device. Usually the box would have two have the doses.
Kelly Cervantes:	<u>07:06</u>	For people who are listening and not viewing this podcast, it sort of looks like just your traditional almost nasal spray, like if you were going to use Afrin or some nasal allergy med. It's very similar in sort of appearance.
Dr. Linda Laux:	<u>07:26</u>	And very simple to use. It'd be two doses in a box, each in a blister pack. So you'd open the pack, just your index finger, middle finger on the one side, your thumb on the injector part. You would put it right at the nostril and then you just push up, push up. That's it. One dose for each nostril. What they recommend is one dose in a nostril. If it's acute, repetitive seizures, wait 10 minutes, see if they stop. Then you can use the other dose in the other nostril.
Dr. Linda Laux:	<u>08:00</u>	If somebody is actively having a continuous seizure, then I would tell the family their dose might actually be both at one time. Again, it has to be individualized and even for an individual, their seizure action plan, what they are supposed to do if they have a prolonged seizure changes over time. It's a living document. So you do an action plan. If they have a prolonged seizure and they still end up in the hospital in the ED, that's what we're trying to prevent and getting the seizures to stop and if it doesn't work then we'd try tweaking the plan, see if we can find something for the child that does work.
Brandon:	<u>08:43</u>	Hi, this is Brandon from Citizens United for Research in Epilepsy, or CURE. Do you know what to do if someone is having a seizure? Go to cureepilepsy.org/seizurefirstaid to watch a short video explaining how to care for someone who's having a seizure. Now back to this episode of Seizing Life.

- Kelly Cervantes: [09:00](#) A continuous seizure, is that the same thing as what we know as status epilepticus? Are these rescue meds only used when someone goes into status? Sort of explain that relationship because I think a lot of us hear that word, but maybe don't necessarily understand what that means and when these rescue meds come into play.
- Dr. Linda Laux: [09:28](#) It's a great question because the definition of status epilepticus has changed over time. It used to be a seizure lasting 30 minutes or greater, but that doesn't help the day-to-day practical life of somebody with seizures. Now it has kind of gone back to a status or maybe even an impending status epilepticus is a seizure that lasts greater than five minutes because that is when you're going to start giving the rescue medications to try to prevent the seizure from being long. And the whole purpose is that you don't want a long seizure, which could hurt the brain, which certainly would land the child or adult in the emergency room, in the hospital. So you're trying to prevent that seizure emergency. But the definition of time is a really interesting one because people tend to use five minutes now, but it used to be 30 minutes, and five minutes again, changed just because that's when you're going to start delivering the medications.
- Kelly Cervantes: [10:26](#) So now there's another med, which I mean, it's crazy to me that we go 20 years with nothing and then all of a sudden in the same year we get two new meds. What is the second med and how is it different than the Nayzilam?
- Dr. Linda Laux: [10:40](#) The second medicine is an intranasal diazepam and the brand name is Valtoco. It's been FDA approved, just FDA approved this month. However, it's not in pharmacies yet. The second it got FDA approved, because it makes everybody very, very excited for us as well. We'd like to be able to offer patients whatever we can to have them stop their seizures. I called the company and they estimated it would be in pharmacies in the next couple months. Hopefully that will be true. It is diazepam as the intranasal medicine. The other, the Nayzilam being Midazolam, again, they're both in that class of medications that are the benzodiazepines.
- Dr. Linda Laux: [11:27](#) So both work in a very similar mechanism. One of the differences for the new medicine coming out is that we'll have different strengths of the dosing of what each puff will give. The Nayzilam, each one of these is five milligrams per puff. It also is approved for children age six and older. That is very, very important for pediatric neurologists because I will have a lot of families and patients six to 12 years of age where this is going to be a huge benefit for.

Kelly Cervantes:	<u>11:59</u>	And why the age difference? One is for 12 and up, one's for six and up. Why? Why is it not approved for younger?
Dr. Linda Laux:	<u>12:13</u>	Solely, that's how the studies were done that got them their approval, so their studies were for the Valtoco six years in age and older. They didn't have a lot of children actually in that study, but at least they had some, and the Nayzilam, it was 12 years of age and older. They certainly could have done it with younger children as well and got that FDA approval. It used to be that many seizure medicines, especially taken on a daily basis, were first studied in adults and their FDA approvals would all be adult, so we would have to use the medicines off-label to be able to use them in kids. Now, the FDA has a very concerted effort to have medications approved in children as well so that we know what the correct dosing and the best way to use a medicine for the safety of the patient.
Kelly Cervantes:	<u>13:04</u>	Do you foresee those age ranges going down so that these would then be available for younger children as well?
Dr. Linda Laux:	<u>13:11</u>	Yes. The one thing they would need to do is probably make a smaller dose, because this, again, is five milligrams. The lowest dose for the Valtoco is also five milligrams. And usually if you get lower than six years of age, you're going to need a smaller dose than the five milligrams.
Kelly Cervantes:	<u>13:29</u>	Right. Aside from the age difference, and certainly in adults where both of these meds are available, why would a doctor prescribe one versus the other?
Dr. Linda Laux:	<u>13:45</u>	These two medicines actually are very little difference between them in terms of they're both efficacious. They both have the same side effect profile. For anybody over 12, they both have the same age of which you can prescribe them. Other than a child under 12 years of age where there's a clear difference, it's not clear what the difference would be between the two. Diazepam, which is a newer medicine, the Valtoco, is a little bit longer lasting, so that might be a consideration if someone's seizure clusters, they tend to have some seizures in six, eight, 12 hours, something a little longer, then I would consider that one more. Midazolam tends to be a little faster acting.
Kelly Cervantes:	<u>14:29</u>	I want to ask about the side effects of some of these rescue meds because if they're available and someone starts having a seizure and you talk about going from 30 minutes to five minutes, why not just give someone one of these as soon as you start seeing them have the seizure? And I imagine that has to do with some of the side effects that come along with these meds.

- Dr. Linda Laux: [14:55](#) Also, some other practical conditions. I have some kids who have multiple seizures a day, so certainly there would not be able to have multiple rescue medications a day. For my patients with Dravet syndrome for example, they tend to have, at least when they're young, not as frequent seizures, but every seizure is very long, literally hours. They do give rescue medications right at the beginning, but all medications have side effects. Yet remember, these rescue medications were made so that they can be given safely at home and at school. The main side effect is that it's going to make the child sleepy. All of these act on the brain. They need to. That's where seizures come from. So they're all going to have that side effect. The child or adult is going to be more sleepy afterwards.
- Kelly Cervantes: [15:45](#) That makes sense. And I've sort of hit on this point a couple times that we've gone 20 years without a new rescue med. Why is that? Why has it taken so long to get a new med on the market? It's just wild to me.
- Dr. Linda Laux: [16:06](#) It's an excellent question. It's been extremely frustrating for the medical community as well because everybody has recognized the need for different types of rescue medications in case the rectal diazepam, doesn't work and certainly different routes of rescue medications. I will say that it just takes a long time to have a medication that you want to get FDA approved. Then you need to do a very long study that can take years in the making and then you have to put a huge application together for the FDA. The FDA needs to review it to make sure that what you're saying is true and that it's safe, which is I think an extremely important job. It takes a long time to get any medicine FDA approved and this has certainly been something that we've been waiting for in the epilepsy community, like you said, for over 20 years.
- Kelly Cervantes: [17:02](#) There are good reasons as to why it can take a long time for these drugs to get approved and hit the market. Do you have any recommendations for caregivers, for patients, for advocates, different ways that they can help this process along of getting these drugs to market sooner?
- Dr. Linda Laux: [17:27](#) I think two ways. One, be advocates on a state and a national level of what is needed for epilepsy. Be part of an epilepsy community, be it the CURE, Epilepsy Foundation of Greater Chicago. There is so many things you can do to advocate for what is needed for people with epilepsy on all levels. And then also, if there is a trial going on, think about it in terms of will it be helpful and not harmful for your child, or as an adult, which is extremely important-

Kelly Cervantes:	18:06	When you're talking about a drug trial.
Dr. Linda Laux:	18:07	Drug trial, but there's also the bigger picture. I've been involved in some drug trials in the last few years including Epidiolex and it does kind of get to the bigger picture of this would allow it to be possibly helpful for somebody else even if it doesn't end up being helpful for you.
Kelly Cervantes:	18:25	As we sort of briefly touched a bit earlier on the seizure action plans and how rescue meds fit into that, can you dive a little deeper into what exactly a seizure action plan is? Who should have one, how you make them and what it consists of?
Dr. Linda Laux:	18:42	The seizure action plan is extremely important. These new medications are wonderful, but if you don't know exactly how you're going to use them, when you're going to use them, what you're going to use them for, then they're useless. I tend to take care of children who have intractable epilepsy. All my patients have seizure action plans. And I think anybody actually should know what to do if they're having a seizure, and that's all a seizure action plan is. It might be very, very simple if somebody doesn't have a lot of seizures. It might be very, very complicated.
Dr. Linda Laux:	19:20	But the bottom line is that the seizure action plans are so the parents, the school adults, family members, loved ones, know exactly what to do if their child or family member has a seizure, what are the care and the comfort they should do, how to keep them safe, what rescue meds to give, when to give them, when to call 911, all of those steps. For my patients who tend to have very, very prolonged seizures, we sometimes have seizure action plans that include what the paramedics are supposed to do. They don't know the child. I do and the family does, and so I make this with the family as to what each step should be, and then when they get to the emergency room, what should be done there because you don't want to be wasting time trying to figure this out.
Dr. Linda Laux:	20:09	So that's what a seizure action plan is very simply is every step. Kids in school I think are required to have a seizure action plan, which in a way is really great because it makes the family and the physician sit down and discuss exactly what steps they want the school to take if their child has a seizure in school, and it's just always best to think about these things before they happen. And as I mentioned earlier in the podcast, again, for some patients who have very intractable epilepsy, these plans may change. So it's not a document where, "That's your action plan for this year. We'll think about it again next year." It's every

time they have a seizure you should go through what worked, what didn't work, at what level and then you go from there.

Kelly Cervantes: [20:57](#)

Dr. Laux, thank you so much for joining us today and for sharing your years of knowledge and insight, and we just really appreciate your time today and all you do for the patient community. I always like to give a special thanks to the doctors that we have on the show because I know it's not an easy job and we just appreciate you all so much, so thank you.

Dr. Linda Laux: [21:20](#)

You're very welcome. Thank you so much for having me.

Kelly Cervantes: [21:26](#)

Thank you again, Dr. Laux, for providing us with your insights on rescue medications. The emergence of the two new medications that Dr. Laux spoke about should greatly improve the lives of many epilepsy patients and their families, but asking patients to wait over 20 years for better options is too long. New and better therapies need to be available sooner. CURE knows the only way to do that is through patient-focused research. That's why we are the leading non-governmental funder of epilepsy research, but we need your support to push science forward, fund initiatives and make discoveries that lead to new therapies and better lives for those affected by epilepsy. To find out how you can support care's efforts. Please visit cureepilepsy.org/getinvolved. Thank you.

Announcer: [22:22](#)

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