

Seizing Life, episode 97
Seizure Dogs: Predicting Seizures and Providing Comfort
Guest: Jessa Kenworthy
(Transcript)

Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.

Kelly Cervantes: 00:18 Today on Seizing Life, I'm happy to welcome Jessa Kenworthy. Jessa is the training director at 4 Paws for Ability, an organization that trains and places service dogs with children and families. Jessa is here today to provide us with an overview of what goes into the training and placement of seizure alert dogs, and how these dogs can support, and assist people with epilepsy and their caregivers.

Kelly Cervantes: 00:43 Jessa, thank you so much for joining us today. I'm so excited for this conversation. I find that seizure dogs are such a hot topic of conversation within the epilepsy community. People have so many questions.

Kelly Cervantes: 00:57 To start off with, can you tell us a little bit about the organization that you work with, 4 Paws for Ability?

Jessa Kenworthy: 01:06 Yeah, absolutely. And thank you so much, I'm so excited to be here and to be trying to shed some light on some of these things. It's definitely a newer field within service dogs. And so, very excited.

Jessa Kenworthy: 01:16 So, 4 Paws for Ability we're a organization based in Xenia, Ohio, and we place service dogs mostly with children with disabilities and also with veterans.

Kelly Cervantes: 01:28 Very good. And how long has the organization been in business?

Jessa Kenworthy: 01:32 So, 4 Paws has been around since 1998.

Kelly Cervantes: 01:35 Okay. And what type of service dogs do you offer and does it vary depending on the disability that the owner will have?

Jessa Kenworthy: 01:48 So we place service dogs, like I said, primarily with children. As far as what the service dogs do, we have a number of tasks that we'll place them doing. Our most common types of placements are our autism assistance dogs and our seizure alert dogs. But we also train mobility dogs, hearing ear dogs, and a number of other things. Also, one of our specialties is that each dog is uniquely trained to help the person that they are partnered with the best way they can. So, multipurpose service dogs can do any number of tasks just based on what the needs are.

Kelly Cervantes: 02:27 Wow. That's amazing that it's so specialized and catered to the specific individual.

Kelly Cervantes: 02:33 And how many people work for the organization? How many dogs are you able to train?

Jessa Kenworthy: 02:39 Yeah, absolutely. So, we have 75 employees and just under 2,500 volunteers. And we place about 120 dogs as service dogs a year.

Kelly Cervantes: 02:53 Oh wow, it's a pretty big operation.

Jessa Kenworthy: 02:56 It is.

Kelly Cervantes: 02:57 And where do the dogs come from?

Jessa Kenworthy: 02:59 We breed our own dogs. Being able to be a service dog, it takes a lot, of course, training but it also takes the right type of personality. So to get more likely a dog's personality that is going to fit being a service dog, we breed all of our dogs to get that. But also, for specific tasks as well. We'll look at that and say, "Okay, we want to breed these dogs together because we want to have a litter of dogs that's gonna be more likely to be able to be autism assistance. Or a litter that is more likely gonna be able to do seizure alert."

Kelly Cervantes: 03:36 Right. So, what kind of breeds are those typically?

Jessa Kenworthy: 03:40 Yeah, absolutely. So, our main breeds are Golden Retrievers and Labrador Retrievers. We'll also do a mixed breed between both a Golden and a Lab together. That's fairly common in the service dog agency. We also, as an agency, will place a Golden Retriever Poodle mix. So families that have allergies can still receive the benefit of a service dog. And some of our placements, we will also place a Papillon, which is a toy breed dog that are not only, of course, great companions is their breed standard, but they also are very alert and make great service dogs for doing things like hearing ear, and even medical alert like diabetic alert and seizure alert.

Kelly Cervantes: 04:23 So Golden Retrievers, Labradors, Golden Doodles, these are all dogs. I think a lot of us are used to seeing as service dogs. Is there a reason that these specific dogs are more typically used and that 4 Paws for Ability specifically breeds for this, what is the reasoning behind using these dogs then, say, a Border Collie, or a Pit bull, or a Boxer?

Jessa Kenworthy: 04:52 So part of that is that the breeds themselves are breeds that their personalities, while they weren't necessarily bred to do these things historically when the breeds were created, they are breeds that are naturally very social and friendly. They're family dogs. They do well in general with the public as a whole. And they've just been bred to be very happy, biddable dogs who like to do jobs and want to please you which, of course, makes them great service docs.

Jessa Kenworthy: 05:25 The other piece is, unfortunately, a lot of public perception, especially with certain bully type breeds, like Pit bulls, the public often, unfortunately doesn't have the best sort of view of them. And even though Pit bulls, most of them are so lovely, sweet, kind dogs, it would be more difficult for many families going in public. They would probably get questioned a lot more. And you might have more of the public, in general, maybe wanting to avoid you, 'cause they're worried about this breed and they're concerned about things. Whereas one of the big things we like to do with our dogs is a social bridge for our kids who oftentimes don't have many friends. So, it's easier for a lot of people to be interested, and want to approach acute fuzzy Golden Retriever versus, unfortunately, seeing a dog that they often have a misconception of is gonna be aggressive.

Kelly Cervantes: 06:24 Yeah, that makes perfect sense.

Kelly Cervantes: 06:29 I think probably one of the biggest questions people have around this in hearing that you breed the dogs yourself, so this is highly specialized, they are trained to their future owners' specific needs. What does something like getting a service dog cost?

Jessa Kenworthy: 06:50 Yeah, absolutely. So, kind of total cost for the breeding of the dogs, the training of the dogs, everything that goes into it, the staff, the supplies for the volunteers, there's a ton of pieces that go into it. And that total cost is for our agency probably around 40 to 50,000. That's not what a family that would be receiving a service dog would be contributing by any means, but that is kind of the total amount that goes into it typically.

Kelly Cervantes: 07:23 And then, I guess, what does the family pay?

Jessa Kenworthy: 07:26 Yeah, so our families, we ask them to join us and help contributing to our cause through fundraising. Our current fundraising requirement is 20,000. So, the families can do this through fundraising outreaching to their community. So, in the end, they may not have to spend a penny at all. It, of course, takes effort to do the fundraising. Some families will choose to

just write a check. It is kind of up to them. We have supports in place to help with fundraising. And then, we have other ways looking at individual donors, and grants, and corporations to kind fill that gap between the 20,000 to the 40 to 50,000 it actually takes to get the dog fully trained and placed.

Kelly Cervantes: 08:15 So, a family decides you know what? We're going in, we want the seizure dog. What does that process look like from beginning to end it? And how long does it take?

Jessa Kenworthy: 08:25 Yeah, so the process starts with applying. There's an application on our website. You fill out the application, there's a small fee that goes through it just to make sure you're serious about this. Once we get in that application, also, it needs to be pretty much a note from a doctor kind of prescribing a service dog saying that a service dog would be a benefit to the partner. And then, we do an interview, a phone interview with a family to answer questions, explain the process, and figure out what the needs are. For the partner what are the tasks that we can train the dog to perform to help with their needs?

Jessa Kenworthy: 09:08 And at that point, once they've finished that, there's a couple other paperwork pieces they need to submit. And then they're ready to fundraise. The fundraise is kind of the part that is sort of the most up in the air. Some families might have one fundraiser and they meet their goal. Others, it takes longer. As a generalization, our fundraising for families takes 4 to 6 months. Once the fundraising is complete, they are placed into our next open available class which, at this point, is about two years out. So then, we have that two years to breed, and train the dog that they will be receiving.

Kelly Cervantes: 09:46 So, we're thinking pretty far out in the future here. And I guess that's important to think about though, if your child is newly diagnosed, or within the first couple years of this, it's good to get in now, and get on the list, get the fundraising going because this is a long lead time. And that makes sense. If you are training the dog specifically to go with the child, then you have to have the child ready to go, and then you have to train the dog.

Brandon: 10:21 Hi, this is Brandon from CURE Epilepsy. Did you know that 1 in 26 Americans will develop epilepsy in their lifetime? For more than 20 years, CURE Epilepsy has funded cutting edge patient-focused research. Learn more about our mission to end epilepsy at cureepilepsy.org. Now, back to Seizing Life.

- Kelly Cervantes: 10:41 What does dog training for seizure awareness alert even look like? I mean, I can't even imagine how you do that training.
- Jessa Kenworthy: 10:53 So of course once, like I said, the start process of we're breeding dogs specifically not only to be service dogs, but oftentimes, to be certain types of specific dogs. Once the dogs are born, their training pretty much starts immediately after they're born with different exercises to get them comfortable with being touched by humans, and different sensory things to kind help their mind grow, and build different bridges towards different inputs. Once they can hear and see, we're starting to socialize them to different visual stimuli, and different auditory stimuli.
- Jessa Kenworthy: 11:33 As the puppies continue to grow their first year is typically very focused on socialization. To be a good service dog you need to be confident enough in any environment and with any person to be able to do your job. If you can't, then you can't focus on your job. It doesn't matter how well trained you are if you're nervous, you're not going to be able to do your job. So, that's our primary focus for that first year.
- Jessa Kenworthy: 11:59 After that first year, we do an evaluation on all the dogs, kind of see what are their natural abilities, their natural talents, what's their personality like? We figure out, all right, are there still some things they need to work on? They get evaluations at 12 weeks, 6 months, and then the year to just help them along and provide support as needed. If we determine they're ready to go on to that next step, we kind of select them, at that point, for the partner that they are going to be working with. And we start tailoring their training to that specific partner. And we bring the dogs back for advanced training and they're in advanced training for months where they learn, at that point, all the specific skills, they need to be able to be a service dog. Our volunteer trainers, as well as socializing them have taught the dog manners, basic obedience, social skills, stuff like that. So they're not coming in loving everything, but with no basic knowledge. But there are specific service dog skills to their placement are being trained in advanced training.
- Jessa Kenworthy: 13:07 And then, after the dogs have been trained, the families are coming to a class where they learn how to handle their fully trained dog. That is a nine day class, at this point. And there are programs that they have to go through before attending class where they do a lot of their education before even coming to class. And then that class, at the end of that, they have a public access test to make sure that they can handle the service dog in public. And then, we go home with all sorts of supports in place, weekly Zoom meetings, monthly check-ins, different paperwork,

just so that we are constantly supporting that team through that first year, as it is often the most sort of challenging as you are transitioning to not only having another family member, but a family member with a job. So, it's a lot so we definitely want to have not just support 'til the, "Here's your dog," but plenty of support after they receive the dog as well.

- Kelly Cervantes: 14:06 That's an interesting point that this is a working dog. This is not the family pet. It is a family member, it's part of, you said, the team. How does that work if you already have a dog in your home?
- Jessa Kenworthy: 14:19 So 4 Paws for Ability, we do not require that you re-home any current pets that you have when you would be receiving a service dog as long as those pets are not going to be aggressive to the service dog. So, some agencies require that you re-home, which makes sense for their program and what they are trying to do. But, for us, we find that it doesn't impact the service dog's ability. We will say, "Okay, this family has cats." So, we make sure that the dog is comfortable working around cats and can still do their job around cats.
- Kelly Cervantes: 14:54 So, Jessa, it sounds like with all the training that goes into place, that the dog is roughly around what? 2, 2 1/2 years old when they're placed with a family?
- Jessa Kenworthy: 15:05 Yeah so, that's a fairly typical age. We might go as young as a little over a year and a half. But that general of timeframe around 2 years is pretty accurate. Some agencies will place their dogs at an older age, which makes sense for what they do and what they're trying to accomplish. For our dogs, having a bit younger can be a benefit because most of our placements are with children. It allows sort the youngness of the dog as well, to be able to be a little bit more adaptable to some of the behaviors that the child might be presenting. A bit older dog might be a little bit less likely to be interested in sort of adapting to some of those, maybe a bit more intense behaviors that the child has.
- Kelly Cervantes: 15:50 Now, you mentioned you do a majority of placements with children. Is there an ideal age for placement that you've seen?
- Jessa Kenworthy: 15:59 No, not necessarily. We will place our service dogs at any age, probably our youngest has been 1 or 2 years old. And we've also had adults that we have placed with where they might be in their 20s or 30s, but maybe they are at a school level of 8th grade or something like that. And so, we will still place, they're still living at home and with family. So, it's not a situation where

you turn 18, and you don't have that option if you need a service dog from us.

- Kelly Cervantes: 16:36 Do schools allow these kind of seizure alert dogs in schools? What has been your experience there?
- Jessa Kenworthy: 16:44 Yeah so, schools is one of our trickier areas. Some of our families can struggle a little bit with that. For our placements that are on a two unit team where it is the partner who is handling the dog, it's fairly easy because they simply just bring their dog to school, and work their dog at schools.
- Kelly Cervantes: 17:02 When you talk about a two unit team, you mean the person with epilepsy and their dog?
- Jessa Kenworthy: 17:08 Yes. [inaudible 00:17:09].
- Jessa Kenworthy: 17:10 That is, correct. Those are the two people. So, just like, if you need a wheelchair, you don't have to get permission. You just come to school in your wheelchair. Same thing with the dog.
- Jessa Kenworthy: 17:18 Where it becomes a little trickier is with our three unit teams. So, for our three unit teams, it is the dog, the partner, and then a trained adult who is handling the dog for the benefit of the partner because the partner is unable to handle the dog themselves. And that can be tricky because that needs to be a one-on-one scenario. And if you have a classroom that has just one teacher and, say, one aide for the entire classroom, then the service dog wouldn't be able to come in that environment because you need someone to be able to be focused on handling the dog for the benefit of the child. So, if the family has a one-on-one aide for their child at school, then that can be trained. And so, the problem is typically within access of the three unit team, if the school hasn't already been providing a one-on-one for the child, it can sometimes be difficult to get one.
- Kelly Cervantes: 18:16 Got it. That makes sense.
- Kelly Cervantes: 18:18 The purpose of the dogs is to alert the partner, or the family when a seizure is going to occur. So, I have a handful of questions here. How in the world does a dog know when a seizure is about to happen when people don't necessarily know when they're about to have a seizure? And how much time in advance is it? Like they let you know 5 minutes before? You get a day's notice? How does that work?

- Jessa Kenworthy: 18:51 Yeah, absolutely. So, for our dogs, the way we train them is scent-based. So there is, we believe, a scent component to the buildup and then occurrence of a seizure that the dogs, when trained, can pick up on. Plenty of agencies will place seizure response dogs that sometimes will pre-alert as well. That's, typically, a natural behavior that some dogs will do, but we train it and we train that based on scent. So, the families will send in scent articles of when their child has had a seizure. And we use those to train the dogs on that scent, so that they learned that whenever I smell this smell, it means a huge party, and a big reward. And so, I want to make sure to tell you every time I smell this smell. So if I were to tell you, every time you smell a vanilla candle, I'm going to hand you \$1,000, you're gonna be sure to tell me every single time you smell a vanilla candle. So, it's kind of like that for dogs.
- Jessa Kenworthy: 19:52 Our dogs alert ahead of time, various different amounts. We have some dogs that will do 10, 20 minutes. And we've had other dogs that do 12 hours, 16 hours, 24 hours. We have one dog that is done 36 hours in advance, an alert. Typically, there's a pattern with it. So, once the family has established that pattern, then they kind of know all right, here's the countdown dog alerted at this time, look forward 5 hours. And that's when we can be looking for that seizure.
- Jessa Kenworthy: 20:26 Sometimes the intensity of the seizure can also determine the dog's alert window. If it's a more mild seizure, their alert window might not be as far out, maybe 20 minutes. If it's sort of a moderate seizure, maybe it's 2 hours. If it's a really big seizure, it might be 6 hours in advance. And then, it's sort of up to the family to set the clock, and then reset it as those time periods pass. And then, they can kind of know, okay, we missed both our 10 minute, and our 2 hour out this means this is going to be probably a really big seizure, and we're looking at 6 hours out.
- Kelly Cervantes: 21:00 Oh, so there's definitely this period of a learning curve with the dog to figure out when their alerts are gonna be, because I'm sure it varies on the dog. And it probably varies on the individual, and the types of seizures that they have.
- Kelly Cervantes: 21:20 Someone with epilepsy, their seizures may change over time. They could change medications, and that'll alter what their seizures are like. Or especially with children as they're just growing, and their brains are growing, and developing their seizures also grow and develop, and not always in the right ways. So, how does that affect the dog when they're trained on this one specific seizure type, or smell, and then that changes?

Jessa Kenworthy: 21:53 Yeah, absolutely. So, the adjustment for our service dogs from training to being able to work with the families and alerting to a real seizure is definitely a transition. We do our best to support our families through that process. And we, of course, train. But it is, unfortunately, not something that we can guarantee. There's outside factors that could contribute to the dog not being able to transition to actually alerting prior to seizures. And if the dog has transitioned in alerting any of those changes can definitely affect the dog, and sometimes temporarily throw them off as they have to of readjust to a new norm, whether that's the frequency of the seizures, or how the seizures smell. We've found that some of our dogs struggle, at first, with the transition in medication because we think it likely makes the seizures, and the scent of the child smell differently than what the dog is used to. And so, they might have a period of time where they miss some as they're sort of adjusting to what the new normal is.

Kelly Cervantes: 22:55 And is that something that 4 Paws helps the families with those transitions, or are they kind of on their own?

Jessa Kenworthy: 23:03 No, we are always, always there to help support our families as long as they reach out to us. It doesn't matter whether it's two days after they've gone home with their dog, or 10 years from when they've gone home to their dog, we will always be there to support them. We have that initial first year of support, which is a lot more intensive. But then, after that we have yearly re-certifications. And then at any, any time families can reach out. And we'll provide them with support. Sometimes it's a situation where maybe we place a dog that wasn't doing seizure alert 'cause it wasn't in need at the time. And then, maybe the child develops seizures later, we can have the dog come back, and learn that additional skill, and then go back to them. So, lifetime support of our dogs and our families.

Kelly Cervantes: 23:48 Oh wow, that's amazing. What a relief for the families. Now, I have to imagine that not every dog makes the cut. So, how many dogs do make the cut? And then, what happens to the dogs that don't?

Jessa Kenworthy: 24:04 So at 4 Paws, our goal is a 40% success rate, which doesn't sound like much, but that's pretty-

Kelly Cervantes: 24:11 No, it doesn't.

Jessa Kenworthy: 24:13 For the agency.

Jessa Kenworthy: 24:13 Yes. And that's because we all have such high standards for our dogs. We only want the best of the best to be able to go on to be service dogs for our families. So, all of our other dogs become available for adoption. Primarily, they will go up for adoption, and be offered to their volunteer trainers who have raised them. And if they are interested, and also meet the requirements, then they can adopt them.

Jessa Kenworthy: 24:38 Some of our dogs might not be the best fit for a service dog, but they would still work well with one of our families who either is awaiting a service dog, or already has a service dog. And so, we can place them as a pet companion.

Jessa Kenworthy: 24:55 And then, if neither of those things happen with the dog, then we offer the dog up for general adoption to the public. And we have a fairly extensive waiting list for all of those.

Kelly Cervantes: 25:07 I can only imagine that wait list is incredible, but that's pretty amazing.

Kelly Cervantes: 25:14 And how long can they work before, I guess, they retire?

Jessa Kenworthy: 25:21 So that depends, of course, a little bit on the dog, and also the task they're performing. If you have a dog who is just doing say seizure alert, that's one of their only tasks. Then that task like a dog's scenting ability is typically something that stays fairly strong with them throughout their life. So, they can typically do that up into an older age than say, a dog that was doing intensive mobility work that maybe was required for stand and brace support, or opening and closing doors all the time, and doing other things that they're just gonna cause a little bit more wear and tear on the dog's body naturally. That dog might not be able to work as long as a different type of dog doing other tasks.

Jessa Kenworthy: 26:03 We hope that all our dogs can have a working life of 10 plus years. That is certainly our goal and our family's goal. But as long as the dog has worked 5 plus years, then we consider that kind of meeting that sort of baseline level. And then, we tell our families, once you start noticing the dog is slowing down, maybe not enjoying going out and about anymore, a bit slower in doing their tasks then, you might consider if you're interested in another service dog, then starting that process for the new service dog.

Jessa Kenworthy: 26:37 It can be very beneficial for many of our families to be able to have a transition between their original service dog and their

new service dog. A lot of times you kind of find a little bit of a mentorship thing happens with the original service dog, sort of showing the new one the ropes and helping them adjust. And it, of course, can be very hard on our families if their first service dog ends up passing before they get their second. So, we always encourage them the sooner you apply the better. We can always push it back, but we it's hard to push it forward.

- Kelly Cervantes: 27:09 Jessa, you mentioned various other tasks that the dog can be trained to do. For a person with epilepsy are there additional tasks that the dog can be trained for aside from just alerting when a seizure is about to happen?
- Jessa Kenworthy: 27:25 Yeah, absolutely. So, one of the ones that we do in conjunction with the pre-alert is an alert during the seizure as it is happening. We also can train the dog to go and retrieve a bag with medicines that are necessary to give the child at the time of the seizure. We can also have the dog, typically after the seizure, provide comfort and support through laying with them, or laying on top of them to provide deep pressure to help of ease the transition out of the seizure. As it can often be very discombobulating and scary. And everything like that. Having their dog right there with them as they're sort of coming out of it can be very comforting. And, like I said, we place our dogs in doing all so many tasks for all sorts of different disabilities.
- Jessa Kenworthy: 28:15 So, it is not at all uncommon for our families to come with us with multiple diagnoses. So, you might have a dog who we might categorize as an autism assistance dog, but there's also epilepsy involved, and maybe also some mobility needs. So, our families, we can pretty much tailor as I said, the dog to their needs. So, you might have a dog that is doing multiple different things that you would sort normally categorize in different categories, but it's all things that they need to help them and help support them.
- Kelly Cervantes: 28:51 And now, I know that you are based in Ohio, but you do provide dogs nationwide, correct?
- Jessa Kenworthy: 28:59 Yes, that is correct.
- Kelly Cervantes: 29:00 And then, I also understand that you have a furry friend there.
- Jessa Kenworthy: 29:05 Yes.
- Kelly Cervantes: 29:06 Perhaps, at your feet that we can meet.

Jessa Kenworthy: 29:08 Yes, absolutely. Let me wake him up. Sniffles [inaudible 00:29:19]. Hi buddy. Okay, come on. This is Sniffles.

Kelly Cervantes: 29:22 Hi, Sniffles.

Jessa Kenworthy: 29:22 He's a Golden Retriever.

Kelly Cervantes: 29:22 That's an appropriate name for a dog.

Jessa Kenworthy: 29:24 Yeah. So, he's in training right now, in advanced training. I'm training him in behavior disruption, which is sort of the comforting support, as well as seizure alerts. So, he is kind of towards the end of his training. And will be going out soon-ish. I can't, obviously, divulge more information than that. But he's working on those things. And he's such a love bug. He's such a sweetheart.

Kelly Cervantes: 29:52 Oh, he looks like it. Oh yes, we're talking about you, you're very handsome.

Jessa Kenworthy: 29:56 He says thank you.

Kelly Cervantes: 30:01 Oh my goodness, what a love. I love it!

Kelly Cervantes: 30:04 Jessa, thank you so, so much for walking us through this process. And answering all of the questions. The work that you do for families is incredible. And we are so grateful to have organizations like yours helping our epilepsy community. So, thank you so very much.

Jessa Kenworthy: 30:25 Absolutely. Thank you so much, Kelly, for having me. I'm very excited about this.

Kelly Cervantes: 30:32 Thank you Jessa for that thorough overview of the training and responsibilities of a seizure alert dog. And the benefits these dogs can provide to improve safety and quality of life for those with epilepsy and their families.

Kelly Cervantes: 30:45 CURE Epilepsy understands this. That is why, for over 20 years, we have funded patient-focused research aimed at discovering new therapies and cures for epilepsy. We hope you will support our efforts by visiting cureepilepsy.org/donate. Through research, there is hope. Thank you.

Legal Disclaimer: 31:12 The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. The information contained herein is provided for general information only and does not offer

medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs.

Legal Disclaimer: 31:34

CURE Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.