Therapy for retaining function

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[00:00:04] **Dr. Dennis Tom-Wigfield:** Hi, my name is Dennis Tom-Wigfield. I'm a physical therapist at the Kennedy Krieger Institute and I worked at the International Center for Spinal Cord Injury. So, today I'm gonna be talking to you about therapy for retaining function, but I also wanted to add in for retaining function as well as gaining function. Maybe I'll just start talking about ABRT, so that's the therapy model we practice. It's called the activity-based rehabilitative therapy. Sometimes we also abbreviate it as ABR. So, if I say ABRT or ABR it's like one and the same, but it's a very aggressive form of therapy. We use it for our acute patients, for our chronic patients, for pediatrics as well as adults. Everybody is appropriate for it. We have people that are coming to us right out of the hospital, and we have people coming to us decades after their injury and we're still able to help them and work on specific goals. Here we go.

[00:00:55] So, here's our objectives. So, hopefully by the end of this you'll be able to identify the key components of ABRT, apply the principles to your home exercise and therapy and understand how therapy can help you maintain as well as gain function. So, what is ABRT? It is repeated near normal activity specifically below the level of the lesion. It's intended to optimize your neurological system, offset the rapid aging, physical deterioration, and secondary complications associated with spinal cord injury. It's characterized by high intensity practice, task-specific and patterned activities, as well as a few other things we're gonna speak about. The ultimate goal is to restore central nervous system function and to promote neural recovery and regeneration. So, who can benefit? People with MS, NMO, AFM, TM, traumatic spinal cord Injury, spina bifida, cerebral palsy, ADEM, GBS, brain injuries, sorry, I forgot to put MOG on there, and strokes. Again, it can be used for acute cases, chronic cases, children, and adults.

[00:01:56] So, with ABRT the focus is really on restoration of the nervous system. In more traditional therapies they're typically working on exercises above the level of your lesion. It's low-intensity practice, non-pattern movements. A lot of it is about compensating for the loss of function. There's oftentimes use of a lot of compensatory devices. With ABRT you want to activate the nervous system above and below the level of your lesion. There's high-intensity practice non-pattern and pattern movements. We try to restore loss of function as best we can and to minimize compensatory devices. So, the five key components are Functional Electrical Stimulation, which you heard a little bit about when Dr. Becker was talking, Locomotor Training, Weight Bearing/Loading, Master of Repetition, Patterned Activity and Task-Specific Practice. So, here's a little video of FES in action. Is the AV guy here? So, anyway, so this is a FES bike.

[00:03:05] It's a special bike that has stimulation as a part of it. So, what's happening is you can see the electrodes on his legs, it's sending electrical current to his skin on his thighs. It's stimulating the peripheral nerve and causing a muscle contraction. So, he cannot contract that muscle volitionally, but through the use of electrical stimulation he's getting a muscle contraction and he's reaping the benefits from that. So, there's a lot of different kinds of therapeutic electrical stimulation. What I just described to you is called NMES. We were stimulating that peripheral nerve to get a muscle contraction. If you just add that to any functional activity it's called Functional Electric Stimulation (FES), but it's really one and the same and then there is TENS which is used for more pain management what Dr. Levy was talking about.

[00:03:46] There's also some new ways we're using electrical stimulation that I'll talk about at the end. So, the therapeutic application for FES is to prevent and reverse disuse atrophy. It can be used as an orthotic substitution. If you have drop foot there are FES devices that you can walk with, so you don't have to use a brace and it's used for strengthening so we can improve and maintain muscle mass. During or following periods of inactivity it helps maintain joint range of motion. It helps you with re-educating and facilitating volitional muscle contractions and it can actually be beneficial for reducing spasticity as well. Some more benefits. Again, to maintain muscle health, the size, the composition, the blood flow to your muscles. It maintains bone health, the bone mineral density, which is very important, especially if you're a primary chair user it can help normalize tone. It's good for your cardiovascular endurance.

[00:04:29] It just helps to optimize your nervous system for recovery. We use it a lot, a lot, a lot on our acute patients with the hopes that it's gonna help them have a speedier recovery and improve their motor function more quickly. So, we're gonna go over some examples of how you can use it. So, in this kiddo, we have some electrodes on his back, so he has maybe a flex posture, some weak back muscles. So, we're gonna put the stimulation on his back to help him sit up a little bit straighter and then to make it FES, we want to pair it with age-appropriate activity. So, he could be playing, reaching for toys, he could be in a kneeling position, crawling, what have you. On the right side is just another setup on someone's back. He's just a little bit bigger than that kiddo.

[00:05:15] Here we are using electrical stimulation to try to help with the spinal curve. So, if he's sideband to the left, his right-sided back muscles are weak. So, we're just gonna load up that right side with the electrical stimulation to try to help pull him into a more neutral position. Our Abs of Steel, here's a kiddo with some electrodes on his stomach to activate his abdominals. So, we can use stimulation with all sorts of activity. We can use it for bed mobility, like rolling over, we can use it for crawling, static standing, kneeling, sit-to-stands, walking, et cetera. So, right here we have a child in a half-kneeling developmental position. We're gonna put stimulation, you can't see it, like on her glute muscles in order to work on that hip stability and strength. Here we have a kiddo that's crawling. So, there's stimulation applied to her hip flexors to help her pull her leg forward as she crawls. You can see the therapist is holding a trigger so they can time the stimulation to make the correct movement at this right time. Question?

[00:06:19] **Audience Member 1:** [inaudible]

[00:06:20] **Dr. Dennis Tom-Wigfield:** So, you can do that. You can put the stimulation on you and let it run, like it's program, but we always want to pair that simulation with a functional activity. So, like when you feel it go on if you have it like on your quad. I don't want you to sit there and like watch TV when it's on it's better than nothing. But every time you feel it turn on I would rather have you, like doing the extension, doing squats, doing something like that because that way you're really reinforcing the brain to peripheral nerve connection with the stim. Yes.

[00:06:49] **Audience Member 2:** [inaudible]

[00:06:51] **Dr. Dennis Tom-Wigfield:** Absolutely. So, we use it on people that have absolutely no motor control and we use it on people with emerging motor control or even good motor control, but maybe you just need that little extra bit of help. So, yeah, we can use it on like the whole spectrum.

[00:07:03] **Audience Member 2:** [inaudible]

[00:07:09] **Dr. Dennis Tom-Wigfield:** Not really, sorry, we can talk about that later too if you have more questions about that. All right, so it can also be used during walking and standing activities. She's working on a modified single leg balance on the left. So, we're gonna put stimulation on her left glutes to help her with stability and balance. Then like I mentioned, for walking, if you have foot drop, you can use devices like the Bioness or the Walk Aide to help you lift your foot so you're not catching your toe. Some other devices also can be put on your thigh. So, if you have problems like buckling, knee buckling, you can put stimulation on your quads, so you won't buckle as much. If you have a hard time progressing your leg forward and your knee really just isn't bending, you can put the stimulation on your hamstrings to help with that.

[00:07:54] Next up, we have locomotor training. Oh, it's working now. So, this is a very good example of locomotor training and we're gonna talk about it. So, LT, it's an activity-based rehab strategy designed to improve sensory motor and autonomic function, health, and quality of life. We provide sensory cues to retrain inherent neural patterns that will hopefully result in better gait. It's really, the emphasis is recovery of motor function using your central nervous system versus compensatory strategies. So, the four principles of LT are to maximize weight bearing through your legs to optimize the sensory cues. So, when the therapist and the trained PT techs are pulling that person's legs through, we're always hitting the very precise muscles on that specific part of the gait cycle. So, when you're stepping, we wanna be hitting your hamstring in your anterior tib. We don't wanna touch any of your extensor muscles and then during stance we're switching our emplacement to hit those appropriate muscles as well.

[00:08:54] We want to optimize cinematics so the therapists are there to really help you have the most normalized gait pattern that we can manage. Then again, that coincides with minimizing compensation. So, LT always starts with the treadmill training typically with body weight support. After that your central nervous system is very excited, very stimulating, and ready to go. We do transition to overground training, it can be walking, it can be standing, it could be seated balance whatever you wanna work on. We're gonna capitalize on that after LT and then eventually wanna be able to apply those skills to community as well. So, the benefits are increased walking speed, walking endurance, walking independence, improved balance, motor recovery, improvement of asymmetry of gaits, improved gross motor skills and just overall well-being and life satisfaction. I know a lot of these were geared around the gait outcomes, but we do put patients in this that are primary chair users. Again, if they're not gonna be working on walking afterwards, we're gonna still work on posture, seated balance, all these things.

[00:10:00] So, our next topic is weight bearing. I'm doing it to me again. I think I'm clicking the wrong spot. Anyway, this gentleman is in a body weight support device. So, he's weight-bearing through his legs and we also have it paired up with electrical stimulation. So, he's getting multiple benefits here. So, what is weight bearing? It's loading across a joint. It's gonna help promote proper joint alignment. It's gonna put longitudinal stress on your bones which we know is very important for preventing osteoporosis and loss of bone mineral density. It also helps to provide muscle co-contractions and it's normalizing that sensory input that's giving feedback to your spinal cord and your brain. So, for legs, we can achieve it by standing, kneeling, quadruped.

This can be both, if you can do it independently, great. If you need assistance from a therapist or a standing frame that's totally fine. It's all weight bearing and it's great for your body.

[00:11:01] For upper extremity, you can do it through seated prop if you're sitting and propping on an arm or an elbow to get weight bearing through your wrist, elbow, and shoulder. You can also do it in quadruped or on your stomach. So, here we have a kiddo on the left in a standing frame. At this point in time, so he's on a vent. He has, you can see a strap around his head to help him with that head control so it's not falling forwards. He has a chest strap on. So, despite his gross weakness, we're still getting him in a standing position. On the right side, we have another child in quadruped, so we're getting weight bearing through his knee and his hip joint as well as his elbow and shoulder and then we modified it. I don't know if he needed a break or if his neck was just weak in general, so we gave him a little head support as well. It was weightless? Okay.

[00:11:52] Weakness, weakness. Got you, got you. It was weakness, okay. So, the benefits of weight bearing, improving bowel and bladder function. If you stand every day, it helps with the motility of that. Decreasing bedsores, improved range of motion, improved autonomic regulation, decreases spasticity, improves bone mineral density, cardiovascular function, motor function, and quality of life. So, next, we're gonna just talk about the mass repetition, mass practice of pattern activities. We know with neurological injuries we need hours to days to months of rehab and exercise. We need hundreds to thousands of repetitions to promote that neural recovery. Also, you know that if you-- the more you use your impaired limbs, the better representation in your brain you will have. If you start neglecting a side your brain will not necessarily forget about that, but the brain mapping won't represent that one as strong as it used to. So, the other component is task specific practice. So, it's a practice of context-specific motor tasks. We're training on the function of it versus just the very specific impairment or weakness. It should always be paired with feedback from the therapist. Again, high repetition, goal oriented.

[00:13:05] So, for example, if you have a hard time brushing your teeth, we don't want necessarily just wanna have you do bicep curls all day long. We're gonna pair a bicep curl with shoulder flexion or adduction. Maybe we're gonna add standing into it to make it more challenging. If you have drop foot, we don't wanna just do exercises on the mat all day long, we wanna actually exercise that muscle in walking. So, we can do stimulation while you're walking on a treadmill over ground and things like that. Every other video is gonna work, I guess. So, here's a gentleman with core weakness working on rolling and the point of this is that he's not using compensatory strategies, he's not reaching over and grabbing the side of the bed and then pulling himself over. He's lifting his head and shoulders up to activate his muscles. He's not using a ton of upper extremity momentum. He's using his hip flexors to also help with that roll. So, he's taking the component of core strengthening into a functional task.

[00:14:02] Don't let bad habits persist. The body and brain learn what we teach it. We know that our patients, when they wanna get something, they're gonna get it however they can, but we're trying to make sure it's safe and its appropriate movement patterns to help promote the correct recovery. So, the 5 Rs of task-specific training, they should be relevant, meaningful to the patient. They should be performed in a random fashion to help facilitate retention and generalize ability to other tasks. Higher repetitions are always, there's reconstruction. If say, transferring or rolling is too difficult, you can break it down into small tasks first and then put them all together and there should be reinforcement from your therapist on what you're doing right, what you're doing wrong, and how to improve. So, that was, like the key pillars of ABRT.

[00:14:51] There's also a lot of other interventions that we're using now. So, one of the more exciting and recent ones is robotics. So, we have lots of robotics now for walking. We saw one earlier today. We also have robotics for the upper extremity. The best thing or one of the good things about robotics is that there's none of the human error or fatigue component. For LT training, it took three people on the patient's body,

one other person controlling the treadmill and the body weight support system. With robotics, it usually only takes one or two people to set them up and then once they're in the robot can just help you take tons and tons of steps. In one of our devices, I can get like 2,000 plus steps in like 30-45 minutes. If I was facilitating each step for 2,000 steps, I would fatigue out way before that.

[00:15:35] **Audience Member 3:** [inaudible]

[00:15:37] So, actually, I was gonna bring it up later. Some of the newer robotics are actually great for people with high tone because again, if I'm breaking through your tone and pulling your leg through for stepping, I'm gonna get tired really fast. The device we have, we put people in there with high tone all the time and it's able to push through it. We usually keep it like slow for the first two minutes as your body warms up and we actually see that it really reduces spasticity and tone after like a full session of using it. So, we're also using whole body vibration. Now you stand on these vibration plates. I don't know if you've seen them online or whatever, but we use as lower frequency to help with tone and spasticity reduction, but then you can also crank it up to higher frequency levels to work on strengthening. We are doing transcutaneous spinal cord stimulation now.

[00:16:24] So, in traditional stimulation we're putting electrodes over a muscle and the stimulation is going to that peripheral nerve and causing that contraction. With this form of stimulation, we're putting electrodes on the front of your body and the back of your body either at the lumbar level or cervical level and we're pushing the stimulation through your body into your spinal cord. So, this is something new that's being researched a lot and we're now doing in our clinic pretty regularly. People tell me that it feels like an e-stim hug. I have tried, like everything that we have at our rehab center except for this, but we can put it up to like five milliamps up to a 100. A lot of our patients tolerated it up pretty high. Especially like at first, if you can only handle like 10 milliamps that's fine, we're always gonna keep it comfortable and hopefully over time you can actually have a little bit more. So, I don't know if you've seen it but there's lot of the studies now about implanting the electrodes directly on the spine. So, this is essentially similar to that. It's just not invasive. It's not gonna be as specific as if you have an electrode implanted in there, but it still can be very beneficial.

[00:17:34] We love our aquatic therapy. You can use it for general mobility, stretching, the warmth for pain reduction. We can also do specific gait training or a locomotor training in a pool. I had one more about that I'm blanking on it, it's okay. Next, we also just started doing BFR which is blood flow restriction therapy. So, we put like a pressure cuff on an extremity, deplete the blood flow going in there to get you into a hypoxic state and then we exercise. So, it's a way of improving muscle hypertrophy and power. So, when you do this, because your body goes into a hypoxic state, you get tired really really fast. So, it's like, imagine if you're doing bicep curls. For me to burn out on bicep curls I may have to use 30 pounds or whatever, but if I'm doing it with BFR and I'm lifting a 2 pounds weight, it feels like I'm lifting a 100 pounds.

[00:18:23] **Audience Member 4:** Don't do that before an event.

[00:18:28] **Dr. Dennis Tom-Wigfield:** Oh, good point. I didn't know that. It's like the people that do that, or they give themselves AD on purpose. Then the last one here is AIH, which is acute intermittent hypoxia. We just began doing this. I don't know if you are all familiar with, like Olympians who go and train at altitude. So, they have lower O2 sats. So, we're doing this in our clinic with a face mask, we control the oxygen levels. We put your whole body into a hypoxic, but controlled state. So, we're constantly monitoring your vitals so the outcomes for that are improved gait, endurance, and speed. I've done it with one of my patients, but we have a few other therapists that have been doing it a little bit more and they're doing the more research on it. So, again, here's locomotor training on the left; nope not gonna work but you can see, there's three therapists there. One therapist is also helping to support his head.

[00:19:20] On the right side, there's a little kiddo in one of our robots. So, once he's set up again, he's on it by himself. The robot is now helping him move his legs. We have stimulation connected to that as well and if you need to the therapist can still get in there and facilitate stepping or whatever needs to be done. So, some considerations for this aggressive form of therapy are acute inflammation. If you're having an active relapse, if you're not medically stable, we definitely want to get that treated first before we're doing these more intense activities. Fatigue is an issue pretty much across all diagnoses as we see. So, we always have to find that nice balance between, we're pushing you hard, we're making you exercise, but we're not completely exhausting you and making you nonfunctional for the rest of the day or the next day. You mentioned spasticity. So, many of our clients have it. So, sometimes it will limit you on what you can do in terms of like locomotor training. However, in general, therapy is gonna help produce that spasticity and typically after using a vibration plate, stretching, et cetera, it's usually manageable and it doesn't actually hold us back. Then we need to be just cognizant of comorbidities, brain injuries, cognitive deficits, pressure sores, things like that. And that's it. Questions? Yeah.

[00:20:39] **Audience Member 5:** So, I've had a lot of recovery over five years and it's still improving after my TM. I can walk pretty good. So, the only issue is that I can't run. You got to be careful about foot drop and tripping. I think over those five years of mine, well, I've been managing my paralysis on the left side after my TM episode, and I think my left leg is now shorter than my right. Is that an imagined condition or is that a result of this compromised gait?

[00:21:14] **Dr. Dennis Tom-Wigfield:** So, yeah, without like, physically assessing, I think oftentimes with spasticity or weakness, it can pull our hip and joint out of alignment. So, it's probably more so like a functional leg length discrepancy versus like, I don't think you had any bony changes that made that leg shorter. I think it's more so you might just have some tight muscles on that side that's pulling your hip up and making it seem like it's a little bit shorter than the other side. Typically like, there's muscle techniques or like manual therapies that can actually fix that with a good therapist.

[00:21:46] **Audience Member 5:** I'll go and track down the PT at my local Kaiser.

[00:21:53] **Dr. Dennis Tom-Wigfield:** Yes, absolutely. Yeah, and like I said earlier, you are more far out from your injury, you're doing great. I think there's always a place for PT with these chronic injuries, right? There's always gonna be some little thing you can work on. It's always just good to have those extra eyes on you and making sure like, you're doing everything appropriately or everything you can and then when problems like this crop up, they can address them as needed.

[00:22:18] **Audience Member 5:** I think I found that they say, "Okay, you're way better than you were, and you can walk across the street, and talk." Sort of saying, "We're done with you." I have to impose myself on them.

[00:22:33] **Dr. Dennis Tom-Wigfield:** Right. So, you've got to find a good neuro rehab. Yeah, because it's so frustrating when, like you've come so far, so they think that, but it's like, but you're still not where you wanna be. There's still goals and things to work on to definitely work on that in therapy.

[00:22:48] **Audience Member 6:** Also, you don't feel things properly and you can have all the therapy in the world it seems like and then you kind of slide back because you're not feeling, it doesn't like, I'm not changing that neuro, that lack of sensation, then backslide into poor gait and stuff like that.

[00:23:07] **Dr. Dennis Tom-Wigfield:** Yeah, definitely.

[00:23:10] **Audience Member 5:** Is there a place for I know Telehealth is now a big thing in medicine, but it seems like a lot of patients if they could maybe videotape some of the work at home in their iPhone or whatever and then have that PT review it and then give them some feedback.

[00:23:10] **Dr. Dennis Tom-Wigfield:** Definitely.

[00:23:37] **Audience Member 5:** Is that something that is in place or is that something that we should look for?

[00:23:25] **Dr. Dennis Tom-Wigfield:** So, at our clinic, it's definitely part of the therapy. Like I said at the end, we send them home with a home program. They have our contact information. We oftentimes during therapy will take videos or appropriate exercises that we want them to be doing afterwards and then if they have any questions or concerns, they can email us, and we can have that back and forth. So, yeah, I would suggest… It's Sarah, correct? If she talks to their old therapist, they should definitely be able to check in with her and modify.

[00:24:12] **Audience Member 5:** So, follow up. Okay, let's see here.

[00:24:15] **Dr. Dennis Tom-Wigfield:** Get you next. Yeah, exactly, exactly.

[00:24:17] **Audience Member 7:** I probably have a question. Comment is, I'm also affected more on my left side and yeah, it definitely feels like a different length sometimes. Okay, it's not, it's just my perception. The question is I've been going to an outpatient therapy, but it's a more traditional kind where it's basically just trying to exercise specific muscles or muscles groups and how do I find someplace in my area that does more functional therapy?

[00:24:53] **Dr. Dennis Tom-Wigfield:** So, where are you from?

[00:24:56] **Audience Member 7:** Boston.

[00:24:58] **Dr. Dennis Tom-Wigfield:** Boston. Project Walk. Project Walk is great. It's technically not run by therapists, its trainers, but they do like a locomotor training and a lot of those specific. They have a lot of that, excuse me, specific knowledge, and know-how. The apta.org website can help you out. I know again, so our program does the out-of-state benefit where you'd come to see us for a few weeks. I'm not sure if other clinics do that like Craig or Shepherd.

[00:25:24] **Audience Member 7:** They do.

[00:25:25] **Dr. Dennis Tom-Wigfield:** They do? Okay.

[00:25:28] **Audience Member 4:** Miami Project does.

[00:25:33] **Dr. Dennis Tom-Wigfield:** Miami Project.

[00:25:31] **Audience Member 4:** Rancho Los Amigos, here.

[00:25:38] **Dr. Dennis Tom-Wigfield:** So, ideally, you'd find one that's close to home, right? So, you can go more frequently, but if that's not an option then yeah, I suggest reaching out to one of those hospitals and trying to get in there.

[00:25:47] **Audience Member 8:** In San Diego, I found one called Adapt and I found this by honestly Googling. Like to rehab for neuro disorders or spinal cord injuries and that's how I found that. So, sometimes Google can be my best friend.

[00:26:02] **Dr. Dennis Tom-Wigfield:** There is definitely way more now than there used to be. Yeah.

[00:26:06] **Audience Member 9:** You can also look at USFC and USOC committee because many areas where there's a sports programs, they have therapists and trainers that are not just for elite athletes, but for developmental programs and just recreation because it covers the gamut of things and so those programs will have information for you.

[00:26:31] **Audience Member 5:** Okay. Great. Thank you.

[00:26:32] **Dr. Dennis Tom-Wigfield:** Sorry, I'm eating into like the Q&A time, but is there one more question here?

[00:26:27] **Audience Member 10:** I was just going to say something.

[00:26:04] **Dr. Dennis Tom-Wigfield:** Yeah.

[00:26:39] **Audience Member 10:** I was just gonna ask about keywords, but you just answered it.

[00:26:44] **Dr. Dennis Tom-Wigfield:** Okay, Google. Google is our friend. All right, thank you. Oops. Sorry, one more.

[00:26:57] **Audience Member 11:** I'm a bit late. Like, you were talking about some of the things, like the vibration thing and the things to make it work out better. So, like my PT guy just seems to put a gait belt on me and have me walk around and then gives me a little stepstool to go up and down and all that stuff. When I'm on my own and like going down a hill I feel my hips are clunking and things like that. Yeah, and like, after listening to you a little bit it's like, hey, you know what? I really need to do more stretching and do things like that. Finding specific exercises that do the stretch. Is there a place to look for that or should I be looking for another neuro-therapist.

[00:27:49] **Dr. Dennis Tom-Wigfield:** I'd probably try looking for a PT that has more neuro-rehab or a clinic that has neuro-rehab near you. Neurological rehab.

[00:28:01] **Audience Member 11:** Once again, I feel like I'm doing, like I'm walking around the parking lot better now.

[00:28:07] **Dr. Dennis Tom-Wigfield:** I mean yeah, like what you're doing with them is not like hurting you by any means. You're still getting the benefits, but it would be nice if you had a clinic that had the more specialty devices and everything, right?

[00:28:14] **Audience Member 11:** Right.

[00:28:14] **Dr. Dennis Tom-Wigfield:** Yeah, because so many clinics are limited by what they have.

[00:28:29] **Audience Member 12:** Is there a terminology for like muscular rehab or is it something if you're trying to Google something.

[00:28:31] **Dr. Dennis Tom-Wigfield:** Just like neurorehabilitation.

[00:28:33] **Audience Member 12:** Yeah, they're not very helpful in my area because they focus really hard, like he was saying, getting up and going and I actually had a situation where my hip was stuck in there and they had to keep yanking it out and then they did stretching exercises. That clinic closed in my area. So, now all I have this other one that was just like he's saying but I don't know the word I'm looking for. Like, I don't need I mean, the electrical but I need something like that. So, what's your terminology? Would be like neuromuscular?

[00:29:15] **Dr. Dennis Tom-Wigfield:** So, the neuro-rehab place is like the general, what you would be going for but what you're really looking for is the myofascial or like manual therapy. Like a manual therapist. Yeah. Yeah.

[00:29:30] **Audience Member 12:** Like, I don't know what even the wording is to find even a needle.

[00:29:59] **Dr. Dennis Tom-Wigfield:** It's sort of just, everyone. A real quick a question.

[00:30:09] **Audience Member 13:** When you're looking for somebody in transverse myelitis, I try to find doctors that are well-versed with transverse myelitis. How would you go about doing that?

[00:30:26] **Dr. Grace Gombolay:** Yeah, that is challenging. So, Google can be helpful if you're able to find somebody who actually lists on their website if they specialize in those illnesses. Right now, there's just not enough neuroimmunologists so not a lot of neurologists who are familiar with these rare neuroimmune diseases. So, often times, you find neurologists who are treating both patients with multiple sclerosis which is much more common and then also the other types of neuroimmune diseases. So, the National MS Society has a list of providers. There's also a way to find medical providers in your area on the SRNA website. If you type in your zip code, it'll also do it. So, there's two different websites to look for those providers. I think there's a few people who are much more rare. So, like the Transverse Myelitis Centers of Excellence. So, we're talking about UT Southwestern or Johns Hopkins. Those are very few. So, most of the time you're gonna be finding somebody who treats both patients with multiple sclerosis and additional disorders. It's pretty rare to find somebody who just does transverse myelitis or just does NMOSD. I mean, we're in this unique situation that we have the world's experts here talking to us about those things. That's a good question of how do you find somebody who even knows what transverse myelitis is? So, yes.

[00:31:47] **Audience Member 2:** For TM, specialized training. So, you talked about UT and Johns Hopkins. So, those physicians that they're putting out everything all should be, there's just not any designation or anything.

[00:32:06] **Dr. Grace Gombolay:** Yeah, so there's a question I'm just repeating for the recording. So, there's a question about, is there a specialized training for transverse myelitis or neuromyelitis optica, and that sort of thing. So, a lot of neurology training will be seeing those conditions as a general neurologist. So, some general neurologists just have some experience with that. If you're training at a big center, then you're more likely to see those conditions just because you have more of those patients. Some of us actually now do neuroimmunology training, which is exactly what I did, we have five minutes left, which is right after I did my residency. So, I'm a full general, actually I'm a both adult and pediatric certified neurologist. I actually did an extra year of neuroimmunology training focused on neuroimmune diseases. So, I saw patients' entire year just with MS, NMO, MOGAD, ADEM, all of those things.

[00:32:53] So, there's a lot of practitioners, neuroimmunologists out there now who are doing these extra fellowships. They're not what we call formally certified. There's a medical organization that certifies all of these things. So, there's just extra fellowships that some neurologists go through. Then my understanding

is that if you work directly with Dr. Pardo at Hopkins, or Dr. Greenberg at UT Southwestern, because they have their Transverse Myelitis Center of Excellence, they're gonna see a ton of transverse myelitis, so they're definitely training their fellows in other conditions too, but they're gonna be especially well-versed because they're working with those specialists. That's a good question. There are some neurologists who do extra training in these neuroimmune diseases.

[00:33:35] **Audience Member 2:** But it doesn't come with an extra designation.

[00:32:39] **Dr. Grace Gombolay:** It doesn't come with an extra designation, that's correct. There's no extra degree that I have. There's no special documentation that I say, "Oh, I've done this, I can just put it on my website thing, I specialize in it." But I did that, yeah, I know. There's no certification or anything for it, but I wanted to do that extra year just because of how important it is and how rare these diseases are and then seeing those patterns, because as doctors and clinicians in training, the more patients you see with a certain thing, the more familiar with it and the more that you know, “Hey, this is typical for this disease” or “this is not typical. We need to look for something else” because a lot of you have shared your stories about, “I came in with the symptom. Nobody knew what was going on. I had this diagnostic journey because they weren't able to recognize these things.” So, for me that extra training was valuable. For me to recognize those symptoms it would be like, okay hey, like now I can tell you if somebody comes in with certain types of ADEM and types of transverse myelitis, types of MRI. I can tell you that they have MOGAD and nine times out of 10 that I'm right. I can guess it. So, anyways go ahead. Not that I'm bragging.

[00:34:42] **Audience Member 13:** The Siegel Rare Neuroimmune Association Fellowship.

[00:34:51] **Dr. Grace Gombolay:** Yes. Yeah. So, talking about the...

[00:34:52] **Audience Member 2:** Yeah, so how does a person find…

[00:34:59] **Dr. Grace Gombolay:** Yeah. So, I think I'll point you back to the SRNA website.

[00:35:01] **Audience Member 14:** Hi, I am from SRNA. I just wanted to invite you if you do have further questions, you're welcome to email SRNA any time. Our email address is info@wearesrna.org. Also, if you take a look at our website, wearesrna.org and just scroll to the very bottom of the page, you'll see a section that says, "Connect, find a medical professional" and there is a way to filter by specialty. It may be rehabilitation; it may be other things that you're looking for in your area or near your zip code. I just wanted to say thank you to our wonderful speakers and for everyone attending this breakout session today. Thank you so much.