Hello everyone and welcome to the TMA Ask the expert podcast series today's podcast is entitled Gaining functional recovery through occupational therapy. My name is GG deFiebre and I will be moderating this podcast. TMA is a nonprofit focused on support for education and research of rare disorders. You can learn more about us on our Web site at myelitis.org. This podcast is being recorded and will be made available on the Web site for download via iTunes during the call if you have any additional questions you can send a message through the chat option available with GoToWebinar. We want to thank the sponsor of this month's podcast. Alexion is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development, and commercialization of life-transforming therapeutic products.

Their goal to deliver medical breakthroughs where none currently exist is driven by the knowledge that people’s lives depend on their work. For today's podcast, we're pleased to be joined by Dr. Kathleen Zackowski and Dr. Rebecca Martin. Dr. Zackowski is the new Senior Director, Patient Management, Care, and Rehabilitation Research at the National MS Society. In this role, she manages and is working to grow the Society’s research focused on clinical and rehabilitation care, as well as the development of the Society’s Wellness Initiative. Dr. Zackowski has 15 years of experience as an academic scientist and clinician at the Kennedy Krieger Institute and Johns Hopkins University School of Medicine. Dr. Zackowski’s studies have investigated the extent that nerve fiber changes in the brain and spinal cord are associated with changes in walking and physical impairments such as strength and sensation. Her research interests are to investigate the mechanisms that underlie sensorimotor impairments and disability resulting from damage to the central nervous system so as to improve disability in people with neurologic conditions. Dr. Zackowski is also an Occupational Therapist with 25 years of clinical experience in adult rehabilitation.

Dr. Rebecca Martin is the Manager of Clinical Education and Training at the International Center for Spinal Cord Injury at Kennedy Krieger Institute and an Assistant Professor at The Johns Hopkins University School of Medicine in the Department of Physical Medicine and Rehabilitation. Dr. Martin received her Bachelors of Science in Occupational Therapy from Boston University in 2001 and her Occupational Therapy Doctorate from Rocky Mountain University of Allied Health Professions in 2008. Prior to joining the Kennedy Krieger Institute, Dr. Martin worked in brain injury rehabilitation in Boston, Massachusetts. Dr. Martin joined Kennedy Krieger in 2005 as a Senior Occupational Therapist at the International Center for Spinal Cord Injury. Since 2010, Dr. Martin has been the Manager of Clinical Education and Training at ICSCI and is responsible for program development, staff training, and oversight of the clinical research program there.
Dr. Martin speaks nationally on topics related to Activity-Based Rehabilitation; she has taught many continuing education courses for rehabilitation professionals in the areas of neurological pathology, rehabilitation, and research. She has been the principal investigator and co-investigator for grants from the Paralyzed Veterans of America Education Foundation and Department of Defense to develop, promote, and disseminate an activity-based restorative therapy training program and curriculum. So welcome and thank you both very much for joining us today.

Thanks for having us.

So to start to get people you know a little bit of context about what the role of Occupational therapy is and what occupational therapist do. Dr. Martin would you mind just starting and talking a little bit about your role as a therapist and the role of occupational therapist in general.

Sure.

So most people are familiar with physical therapists and a physical therapist job is to evaluate your movement and help to restore specific movements. Mainly they focus around strength and endurance whereas an occupational therapist job is to take that movement and help you put it together using pieces of strength endurance but also cognition and coordination to engage in more meaningful activities.

And so an occupational therapist is really going to center your goals around the activities that you want to do. So if bathing is important to you or feeding yourself not just things like Can you bend your elbow but really how you put those movements together.

There's generally a greater concentration on upper extremity function by an occupational therapist than there is by a physical therapist and an occupational therapist may also introduce modifications to the task or environment in addition to specific patient centered interventions.

Great, thank you so much and Dr. Zackowski

Would you mind if you have anything to add and talking a little bit about your role as well.

Sure. Sure. I think other things that come to mind you know occupational therapies role kind of evolves into a little bit differently at different locations. So at some institutes or clinical centers occupational therapy may be heading up things like waiting for wheelchairs. We also are we often do as as Becca said upper extremity care including fabricating split as well as providing exercise for a upper extremity impairments.
We also have training in things like how do you modify your home or how do you modify your work environment to be most efficient or most effective given that you may need to adapt your activities a little bit more because of a pathology like TM. So we are sort of the people that should help you be able to do what you want to do with your life. And that's really very multifaceted which is why I think it is hard to define occupational therapy. We're not just the exercise people. We're not offering you medications. We're offering you adaptations and ways to make your life more make you be able to enjoy what you like to do in your life. And so this makes it sort of a vague definition but it's kind of on purpose that can really tailor the interventions that we provide to each person pretty individually because your goals are very different from one person to the next.

So my role is I am still in clinical care but it's a much smaller extent from my role now is to really try to encourage occupational therapists and other scientists to study things that could benefit patients. So not only what medications work or don't work but also what kind of rehabilitation intervention can be most effective and that help people with pathology like transverse myelitis. So my role is I have an administrative part and I have a research part and then I have a small clinical part as well. So occupational therapist can do a variety of things in addition to their critical role.

Thank you so much. I mean I think you both conveyed how much each of us do and how varied it can be at least in my experience as well working with occupational therapist. They're there to help with you. I want to be when it comes to networking. You know doing something or just wanting a strength in certain areas that they have covered that or are going about after that as well. So thank you both very much for your insight on that. So where to jump into some of the questions we got from our community. So one question was that you had put together a home exercise routine at home. Are there specific exercises that are better than others or what's the role of a home program in occupational therapy?

You want to start Becca? Then I can add on you want to show us and we can switch off maybe for you.

So I think that the home exercises are really valuable and super important for people who have any kind of neurological impairment. Even if you're going to therapy on a regular basis you might only be getting therapy for an hour or two hours and in a really lucky situation at a time a couple of times a week.

But if you think about how much activity somebody with a normal neurological system is getting all the time you need to be able to sort of replace some of that activity you've lost because of the injury or disease with some home exercises. So it's not enough to just go to therapy three times a week.

You have to be putting in work at home. You know the World Health Organization recommends a minimum of 150 minutes per week of moderate
activity for all people and people with neurological disabilities rarely meet that goal.

And so I always explain it to my patients like you're driving a really special car and you got to put a lot of maintenance into this car now. And so it's not just what you do in therapy but also your home exercises that become important things like cardiovascular activities like cycling or walking or using an elliptical machine. Are just as valuable for patients with neurological injury or disease as they are for a normal population. So that's something that should be included in everybody sort of home routine and then specific exercises are really dependent on your goals and deficits.

So if you have a lot of weakness in your arms and your goal is to be able to feed yourself your therapist can help you to identify exercises that will work on strengthening the specific muscles that will get you towards your goal and then that becomes the things that you should work on at home.

And just to add I agree with everything Becca said but to add to it part of the importance of going to an occupational therapist to get a home exercise program to improve your function is that it's the it's the form you use as you exercise right. So

anyway I can sort of go you know do exercise sort of haphazardly or not really thinking about it and just kind of get it over with. But there's evidence now that you have to be aware of what you're doing and do it with a with the right form so that you're getting exercise can benefit you the way that we've intended it to. So it's really important to pay attention to what your therapist says. Have them write it down. Really be able to use the instructions that they give you. Make sure you really understand them and then try to set it up in your home as similarly as possible. I even have people videotape themselves doing the exercise so I can so I can comment on it because it's really hard to know if you're doing the right thing and if you're not doing exercise really correctly you're not going to benefit in the same way.

I mean it's similar to anyone who's done any kind of baking if you're kind of haphazard and you don't put exactly the right ingredients and you don't get the same product. So it's really important that the point of having a therapist give you exercises vs. going to a gym and using a generic trainer that we really are taking into consideration what limitations your pathology may have and what your goals are and trying to combine that information so that you get the most out of it. It's not just something to take up your time. It's not just something to make you fit. It's something that makes you functional for I think the important part of what OT brings to this

really makes sense.
I know it's also hopeful for home program and so I know Kennedy Krieger Institute to send people home with a whole program that has pictures and stuff which makes it a lot easier to recreate what you did therapy at home as well. I found that really to be helpful.

Yeah. I think you should never like Kathy just said you should never be afraid to ask her therapist. Am I doing this right. I often when I see patients who I haven't seen in awhile the first thing I ask them to do is to show me their home exercise and show me what you have been doing and then be honest with me about what you haven't been doing so I can help fix that. Right. If it was too hard or too easy or caused you pain you need to make sure that you're talking to your therapist about that.

Right because I think sometimes people will come back and say you know this is just too easy. I decided to modify it because it was too easy for me. And sometimes the modifications are good but sometimes there's a point to why it might be too easy. It might be that we don't want you to strain yourself because when you start training you use extra muscles and then you might not be getting the same benefit. So the little details are what I think make some people say well I just don't understand all this. I'm not going to exercise at all which I don't want to get that message either. But I to be kind of aware that exercise has something to it it's really the way we would design a program for you it's not the same way as she would get at a generic gym.

It really is specific to what we're trying to get to what's your improvements for and so ask questions. A third is make sure that you understand what are the important parts of this and what can I modify if I do feel like it to easy that you know how do I do that in the right way for that you are empowered to make some changes but you really are you know understanding what the ultimate goal is for it.

Yes that's a really really great question and I'm glad it's brought up so you know ideally you get to an occupational therapist that has a background in neurology and you get you get this expert. Otherwise things you can do would be what. One thing I suggest that people can you get to facility one for a good evaluation and to get the home exercise program even if it's far enough away that you can't go very often. But you can at least get access that expert in there in that clinic. Another way to do this is to go to a physical therapist and ask them are there occupational therapists around. And if you live just to rural to have any of these conditions very accessible and one that understands TM which might be much harder to find. You know part of it is you're going to have to do some learning on your own.
15:20 And so that would be you know understanding what the exercises are what exercises are going to provide you with increased strength and in which muscles. So you can do a lot of this by looking online and reading. But I will give you know my caution is that the Internet is a wonderful thing but it also is not very well audited. So you can get information that is false or not and not correct. And you might not know that. So trying to learn what you can but ask questions to the professional. You do have access to if you have access to a physician bring them through exercises and say are the things that seem reasonable to you. You know they're not trained the same way their best is but you can but you can at least have that person make sure it is safe for you.

16:13 Another good place to go will be a conference. So there's a TM. I know they have conferences. You can bring information there and see if there experts there that can talk with you. I don't know if you have other suggestions that's a really important problem.

16:31 Yeah I think the one thing I would highlight that you just said is if you're going on the Internet you can't just go to like Wikipedia and YouTube you want to go to like the TMA Web site or the Kennedy Krieger Institute Web site or the MS Society and those places will link you to other reputable Web sites to get resources and information from them.

16:53 They even have a National Honor Society has videos you can follow to do basic exercise and you know I'm guessing I haven't been on the TMA Web site recently so maybe you can talk to what's available there.

17:09 So we have several that, don't have videos that particular exercises but we don't have several and videos and podcasts about various rehab topics. So and I do know also in my experience here I have some apps as well from different rehab centers that have different exercises so depending on your level of injury I don't know how I would personally use them all that much but I think those things are starting to come out a little bit more as well. Yeah.

17:42 And there's even I'm sorry there's even there are. There's a journal that is a video journal that I've published and with the goal of allow it allows patients to access the video. And what I published was an exercise manuscript trying to teach patients and or therapists specific exercises that are useful for people who have weakness in their hips. And so for adults who have had this in their weakness in their hips and I like to make that available to you.

18:20 But it's definitely a resource with the purpose of trying to make it accessible to people across the board who might not have access to a therapist and that's very good.

18:36 And then you know in terms of also if someone doesn't have a therapist that specializes in TM for example with someone who specializes in for example
spinal cord injury or other neurological conditions do you think they would be able to see with TM, NMO or ADEM the yeah I do.

18:59 And I think particularly people listening to this podcast and people who are a part of the TMA are really well educated about their conditions and so don't be afraid to bring that to your therapist to you and be like I might be the only person you ever see with TM in Nebraska. Let me help you. Let me share what my experience has been with you.

19:15 There's also I mean you can go. So Becca is a really good example. So she works in a spinal cord Institute So it's really focused on spinal cord injury but TM is one form that right so you can generalize the information if you can get it from some spinal cord specific resources that might be also very reasonable for someone with TM.

19:56 Thank you. You mentioned that TMA has a conference symposium coming up in October in Columbus Ohio where we'll have talks about rehab. So some information there as well. So going back to some of the questions we didn't get a question about this person has had occupational therapists come to their home as well as an outpatient. And they found that some were more helpful than others when it came to walking. And they are wondering you know we've been talking about home programs. Is there something that they can use at home and help them. They do have a walker. But you know it's limited getting around without help. Dr. Zackowski?

20:37 So the question is really they're using a walker but they want suggestions for equipment or for exercises.

20:45 I'm not sure. I mean it's just it's really inexpensive look what they're saying. But I think also we can extend it to others who this may be relevant for and for.

20:56 Exercises that help particularly walking or things that can be done to help where the those two things come to mind one.

21:05 I'm a big advocate of standing frames. When people have trouble walking even just standing as an exercise. And so you can just stand at a counter and watch TV or play cards or do something with someone else. And that act of standing is exercised. And especially if you're kind of aware of your posture and you're not leaning on the counter the whole time but you really are trying to hold your weight on your legs while you stand. That's one good way to get exercise in an environment where you might not have a lot of help but you still want to be doing something for yourself and you can you can stand independently again you know holding onto a counter. And it can progress all the way to the standing frames provide support for it so that you don't have to do nearly as much.
Provide support at your knees on your hips and your torso and that allows you a safe place to stand and get some exercise. It's not only good for your leg muscles in your trunk muscles that it's good for your blood pressure and things like that that are sort of a physiologic response that you get from exercise as well. Now if you’re asking about exercise and the need for expensive equipment it really is not necessary. I mean there’s more and more evidence that just plain physical activity any kind of physical activity that you enjoy is better than sitting on the couch or sitting in a chair the whole time. So if that means that you have to go in your wheelchair and use her arms because that's your way of getting physical activity I mean that's great. It also could mean I'm just going to.

I'm always going to walk to get the mail. I'm not going to I'm not going to ask my significant other to get mail I’m always going to do it myself because that's a little bit of a walk. I'm going to you know I’m going to make sure I walk around the block once or once a day to make sure I get a little bit more exercise so exercise can take on the role of just being activity something you’re doing so that you're using the muscle your muscles and your body and you’re moving or it can be more focused and be more exercise driven where you’re sitting on a stationary bike and you’re cycling because that's one way you can do it safely. There's no risk of falling on a stationary bike versus walking might pose a risk of falling and if you’re alone that might be not a not a good option right there also.

You don't need equipment to do resistance exercise. And we all know there's so much evidence that as we age we need all be doing resistance type exercise. And while the endurance exercise. So, anyone on a call that's older than 40. We should all be doing some kind of resistance training. And you want to be very careful how you start it but you don't need equipment you need you know expensive equipment. You can get hand weights that are very small one or two pounds and weighs up to five pounds. You want to again be sure you're doing things safely so you're not causing yourself pain. We also use them in the lab we use resistance bands quite a bit.

And we found very good success with just using resistance bands that are anchored to a door or anchored to your sofa. Something that was not going to move very easily and that you could push up against and do just as if I could exercises so that the windows wide open on how you can get exercise outside of expensive equipment and. And. And you don't always need a walker to get exercise you can do things outside of walking that can provide some improvements. I hope that answers the question and Becca you might want to add to that.

Yeah I think the only other thought I would add is that there are a lot of gyms in the communities have adapted exercise equipment particularly at YMCAs. They make a big effort to include people of all abilities. And so you'll see a lot of things like recumbent cycles or even arm ergometers or cycles that you can use and that often winds up being much less expensive than buying one of those pieces of equipment for yourself at home.
25:30 So it's a great suggestion. And then the questions.

25:38 So you know when talking about weight training and we look at how much weight are invading and even routine to follow if you do heavy weights or lighter weights and more reps buried the muscles or the goal is.

26:01 I think the most important thing when it comes to resistance training and like Kathy just said is that you have to do something.

26:07 And so if you can do 12 repetitions at three pounds instead of five repetitions at 10 pounds then you should do what you can do. Do the three repetitions or three pounds and 12 repetitions. There is a role for both low weight high repetition and high weight low repetition when we're talking about conditioning muscles in a particular way and your therapist can help talk you through those. And what phase you really need. But I don't want to tell people like you should only do it one way because the fact is they're both important but something is better than nothing.

26:49 Yeah. Yeah. I second that. I think I think the excuse which I still think is an excuse whether you have TM or you don't is that you do nothing. So there's always something that we can but you can be doing that is safe and healthy for where you're at. It's finding out what to start with. But I think it's often the big the thing that stops people.

27:18 Also. I think that people particularly people with some sort of injury or disease are often afraid to be uncomfortable and exercise and resistance training. It shouldn't be painful but it's probably not going to be comfortable particularly when you first start. So that's where a therapist comes in really handy because they can really help guide you about what's pain versus what's discomfort and what's safe for you and where to start. But you should expect for it to be difficult.

27:52 That's a really good point actually. For I feel like that should be. People should really listen to that because I have found even just with normal aging that exercise gets to be more uncomfortable as soon as you stop doing it for a while.

28:06 So just because you have any pathology doesn't change that normal that normal part of aging where just moving more becomes more effortful as we get older. And so it's more of a reason why we have to stay fit and not go through the cycles of I'm going to you know I'm going to exercise and then I drop and I don't do anything for a month and then I'm I go now I got to start again. And that's that much more effort than if we can try to find physical activity and exercise that you enjoy enough to keep it going throughout the year. Right. So keep it going even if you have to modify it with the seasons. So I can't be outside walking in the winter because of the snow. How am I going to adapt that for the equivalent kind of thing that I can do indoors safely and within my set of resources right can I walk into a mall.
Can I go to a gym like the YMCA. That's a really good suggestion. Can I use free videos online to do exercises in my home. Can I invite a neighbor over so that I'm more apt to actually do the exercise thinking really creatively is not specific to TM and it's a problem for everybody. But having a disease just makes it even seem a little more daunting is my guess.

And here's the really good news, the really exciting part is that there is a lot of evidence to show that activity into the nervous system so increasing the amount of input you're giving your nervous system through exercise and activity benefits your whole nervous system.

So if you for example are have a really difficult time walking and you're able to do exercises just with your arms you will find over time that you might be able to do more exercises with your legs also. And again a therapist can help you guide these things. But Kathy's point about taking an exercise that you like and you will stick with is really the most important part and that you'll see changes in your nervous system and your body and your muscles and your joints and your bones and all of these things will start to come and they'll come through your whole body too.

Exactly. And there's evidence right. We know that that exercise can help with depression to help with cognitive changes.

All of those things are benefits that have very few side effects versus the many medications that have this list of side effects that you might benefit in one thing but the cost of it in side effects alone is very difficult. So exercise doesn't have that long list of side effects especially if it's done under the guidance of a therapist.

Thank you both. We also question about deep tissue massage therapy. So you know all you need for us. So that numbness also that curtailing feeling the abdomen. So there are you know that they reached a therapist where they are going to massage therapy. Is that a difference or how does that play into the whole occupational therapist?

I'm not sure I understand. I couldn't understand all the words that you just said. So you're saying if the sensory changes. Is that what you mean. Yes sensory changes. Numbness? How does that affect exercise this.

Question came from someone who was diagnosed with transverse myelitis in 1989 is now seventy-two and they've been doing deep tissue massage therapy recently been helping with pain. And on this the curdling sensation that people experience So just wondering if massage therapy in other part of what occupational therapists do or something separate or if it does play place the role of therapy.

Thank you.
32:23  understand now from my experience massage therapy is not part of directly from occupational therapy. There are massage therapists who have training. We have some training in massage but it's in my experience it's been more specific to massage for scar tissue. So back to my goal to give you a different version of that but there are massage therapists who are trained to give massage and the evidence for its effectiveness is very spotty. So

32:56  that is what going to limit your insurance company. In many cases from covering it. But I'm not saying it doesn't help many people I have a lot of patients who have said it really it's something they really benefit from and they don't want to stop. And so. So I don't find it under the occupational therapy realm.

33:14  In my experience

33:19  so I think when occupational therapists do more manual work and more of something called myofascial release which is addressing the tissue that lies between your skin and muscles and sometimes causes restrictions in movement which is not traditional and deep tissue massage like this person is is describing it. It doesn't feel good but can help to break up a lot of restrictions and free movement. That would be something that a skilled therapist does which is different from massage therapy. Although I agree with Cathy and if it makes you feel better and therefore gets you to move more I'm in support of massage therapy. Follow up questions what we are talking about.

34:10  Here. So what you know is so there is like should be or. Often some level of discomfort doing exercise after you know you're doing you're working out. You know as we said a question about sort of discomfort is connection to overheating with excursion and that triggers symptoms exerted some and found that they feel dizzy tingling in their extremities you know anxiety sensations their chest. Numbness that sort of thing.

34:44  So can exercise lead to overheating that can lead to these symptoms my understanding when you exercise it there's a physiological response. And

34:58  we know in multiple sclerosis specifically that when you when you warm up your body using exercise. This changes the structure of Myelin . And so this causes many people with multiple sclerosis and maybe TM even though the pathology is different. But you all we all have Myelin which is covering

35:20  around the axon that Myelin structure changes as it heats up and that can allow people to feel symptoms that they felt in the past. And as soon as they cooled down they find after they finished exercising they will go back to their baseline so it won't cause the pathology to progress in any way but it can definitely be very uncomfortable. And many patients describe it as just sort of scary because they don't want to feel this tingling or numbness or the sensations that they felt in the past. And so in my experience that is different.
And the discomfort we were talking about when you're exhausted and yourself you want to have a little bit of muscle fatigue for example you want to be out of breath a little bit. You want to maybe have some sweating. Those are the positive physiologic responses to exercise that we were. But you need to be to learn to be comfortable with them in order to make gains. But if you're getting dizzy when you're exercising that's more dangerous. So that is something that you need to monitor maybe your blood pressure as you're exercising. You need to be sure drinking enough water because even just being dehydrated can make you dizzy when you exercise. And dizziness is important because then of course if you're dizzy you might fall right. So then there's a high higher risk of injury and you don't want to put yourself at higher risk of injury and you're exercising of all things right.

Exercise is supposed to be helping you. So if it's done smartly you know you should have. You shouldn't be putting yourself at greater risk of falling you need we you know we need to make sure you're in an environment that is safe but there is going to be discomfort from exercise.

And that's what I was trying to sort of sell out.

Maybe some of the differences I'd agree with all that I think too we talk about the discomfort that you're experiencing during the exercise raising your heart rate exerting your muscles. And as Kathy described all of that sort of goes away when you stop exercising you might feel it for sort of 20 minutes maybe even 24 hours if you had a particularly hard workout. But it should resolve and go away. And I think sometimes people with MS or TM are afraid to exercise because they're going to worsen their pathology.

And as Kathy described that changes related to exercise resolve. Right.

Right. And is it possible that someone may like autonomic dysreflexia from exercising and then similar symptoms or is something else entirely.

It is very possible that somebody gets something like autonomic dysreflexia in response to exercise. Again that would be something that resolves pretty quickly once you discontinue the stimulus that caused the dysreflexia in the first place. And that's again another really important spot for a therapist to help you tease out what it is that you were doing that caused the dysreflexia and then how to modify or change that activity but still get similar benefits. It.

Makes sense.

And so we also you know we want to convey. You hear people talk about issues that bladder and bowel problem. And so this did get one question about you know that diagnosed with TM that she lost bladder control it's a catheter attached to a bag it's impacting her self-esteem and socializing. Are there roles
for occupational therapists. You know to manage bladder and bowel issues are strategizing ways to do that.

39:10 Yes. So I think are sort of two avenues here. One is the function of the bladder and changing that and two is managing the bag that dressing the hygiene associated with having a catheter. So in that second area you know things like if they're really the bladder and has lost full bladder control the patient has lost full bladder control but doesn't like having an indwelling catheter which requires you to have this external drainage bag that the therapists in conjunction with the physician might help you make the decision to move to something like an intermittent catheterization and an occupational therapist could help you learn how to do that how to set up your environment how to transfer in and out of your wheelchair manage your clothing and your hygiene. All of those sorts of things so that you no longer have the drainage bag but could empty into some sort of container and then get rid of that urine on a regular basis.

40:14 So OTS can help in that way in terms of modifying how you're managing your bladder. There

40:22 are also therapists PTs and OTs who have specialized training and pelvic floor health. And so if there is some bladder function remaining and that would need to be decided by a doctor with a urodynamic study. But if there's some bladder function remaining you. There are therapists with specialized training who can help to retrain the muscles of the bladder and the pelvic floor to restore continence.

40:54 It's a really difficult problem to address. And so the use of sort of very coordinated use of medication as well as your management are at adaptive measures is going to be what's going to be probably the most effective.

41:12 So. So I think this is where having a physician and a therapist involved might be the most the best solution.

41:30 Right. That's where having a team to coordinating different aspects of someone's care. Great review. So long you know we talked about therapy as trying to get back function as well as you know adapting your life to do things a little bit differently.

41:58 So to accomplish things in sort of a different way. Are there any. You know is there any evidence that. occupational therapy or any sort of therapy can help regrow myelin or repair those connections that are damaged, like electrical stimulation or gait training, anything like that? Do you want me to start Becca

42:24 Or do you want me to start? You're the myelin expert, so you can go first.
So if we know if it's you know it's a golden question right. Because if I were to tell you there's this one thing that you could do and that would increase the growth of your connection in your spinal cord. Everyone would want to do it.

And the reality is you don't. I'm not right. Yes.

But there is hope so I will tell you that I know there is evidence that that motor learning can happen can new motor learning can happen in an adult. So initially we've gotten this only happened in children during development periods and now you know if you know that if you're damaging your brain and spinal cord you can make changes that are activity driven. We what we don't know is the exact scene. We don't know how to. We don't. We're not very good at tailoring this to each individual just yet. But but there is evidence in animals and humans that that exercise can be a trigger for this. It changes the chemical makeup of your spinal cord so that you are putting yourself at the best possible position to remyelinate and and facilitate new connections. Only and I'm not speaking generically like that on purpose as much as I want to be very clear. We do know that it can happen. We just don't know as far as I'm aware the details of exactly what you need to be most effective.

And the reality is that probably each one of us has a different amount of potential for growth and change in these neuronal connections. And so when you're an adult with transverse myelitis is good news right. Because this suggests that there's hope for just using activity. What I think is the most realistic response is that activity probably plus some kind of medication is going to be what we're going to find is going to be most effective. But we don't know that's been happening very well just yet. And so my best advice to people is to stay as active as you can. So physical activity can't be passive for these changes to occur in your brain and spinal cord they have to be you're actively thinking about what you're doing as you're exercising pushing yourself to a certain extent that you're facilitating your body to work at its most healthy way.

And my guidance again would be to go either physical therapist or an occupational therapist to get yourself as active as possible. And figure out what kind of exercise you can continue. Becky you the more specific examples. I think probably from your work and from the Spinal Cord Institute.

Yeah. So I always describe it because I'm not as smart as Cathy. I feel like I think about it in more simple ways. And so I think about it as they like their little Pac-Man in our nervous system inside our spinal cord and our brain whose job it is to eat up damage and lay down new cells. The thing is that those Pac-Man only go to axons or wires that are active. And so when you have a neurological injury like a spinal cord injury or transverse myelitis or MS those axons go dark and the Pac-Man don't know how to. Don't know to go there. And so like Cathy was saying what we do know is that activity specifically below the level of the lesion but also above helps to turn on those axons and direct those Pac-man. What we
don't know yet is how much activity they need and how long this Pac-Man are going to take.

46:14 We have some better evidence in animals but unfortunately animals are not humans. And so the rules don't apply the same way.

46:23 So our program is built around this idea of providing repeated near normal levels of activity into the nervous system to optimize the nervous system for every turn on those axons and get the Pac-man to do their job and offset the rapid aging and chronic complications that patients with spinal cord injury and transverse myelitis and MS and NMO have. And so all the things we've been talking about up to this point in this podcast have been surrounding the physical integrity of your body making sure that you are healthy that your muscles are working that you prevent breakdown of your muscle and your bones through exercise.

47:01 And as Kathy was just describing it turns out that same exercise is what you need to mobilize the body's own capacity to repair and regenerate that Myelin.

47:12 We do therefore a lot of electrical stimulation to get body parts moving that are not able to move of their own.

47:22 Also things like vibration and in certain structured exercises but like Kathy said it has to be active. You can't fall asleep during therapy. That's why massage therapy doesn't count as active occupational therapy right. You can't just like have somebody come in and stretch you. You have to be making the effort too because there's there needs to be a coordinated down message and up message in your spinal cord in order to turn those axons on.

47:54 Our current research is looking at a particular kind of stimulation that is applied across the surface of the skin but directly to the spinal cord which helps to unmask hidden connections. So we know that in all cases particularly in cases like transverse myelitis and MS there is a fair amount of preserved tissue still in the spinal cord.

48:18 And but it's not communicating with enough volume and coordination to restore normal function. And so this stimulation that we're providing to the spinal cord helps to basically turn up the volume on those connections allowing them to be more efficient in their communication. And so we're seeing that patients are recovering walking recovering sensation bladder function things like that. In response to this simulation plus therapy. So it's not enough again to just wear the therapy and be a passive recipient. It has to be in cop to where the stimulation and be a passive recipient as to be in combination with therapy. So that's the kind of stuff that we're researching now. Again there's a lot of questions about dosing and timing. And do you need to do it forever. Is it is it like a vitamin you're going to have to take every day for their life or once you
can walk. Will you be able to walk for the rest of your life. And we don't know those answers yet.

49:26 But that's what we're working on now. We also don't know. So sorry.

49:31 So we also don't we also don't know to the original question whether this recovery of function is related to improvement in in these hidden connections unmasking these hidden connections or if we're actually remyelinating or we're regrowing axons that were lost to the original injury and we don't know that because people are really resistant to let us dissect out their spinal cords.

49:57 But maybe one day we'll have a better answer from more animal based models

50:02 I was going to bring up other experimental things that we've done besides you know dissecting out your spinal cord which sound a little painful.

50:13 So we just did a study with Mike Levy (note 1) where we had patients with TM using a combination. So they use a derivative of 4-Aminopyridine in which I can't think of the regular name if you care to give it here.

50:13 Ampyra yes. Ampyra. They use Ampyra

50:38 And we were it we're kind of figure out what Ampyra is known in multiple sclerosis to improve walking in patients with MS to a small percentage of people it doesn't work on everybody. No one has any idea why it's working but it is what it is. But it's FDA approved for this particular thing. So we got warranty. Why don't we see what we can do. So what we did in the laboratory is we tried to probe whether the neurons were changing as the people were on this we're on Ampyra and I'm not give away the whole answer because Mike and I are writing the papers right now. What I can tell you that there are things going on in the laboratory that you hear about experimental studies and they're looking for patients with transverse myelitis you're all a very rare group.

51:29 So find out more information about it see if you're truly interested in it. There is no pressure that you have to do it but it might be something that would be that would that help us understand the disease better. And in that way we would understand how better to intervene and make improvements. And the study that we did was very safe but it required a lot of effort. So patients had to literally take this medication but they also had become in the laboratory for a three hour visit. Then they had to keep taking the medication come back a few weeks later for more testing go back home keep taking the medicine. This went on for eight 12 weeks. And this is a big investment in time. But it is the way that we're going to better understand how the medications work and what's going on in the brain and spinal cord.

52:20 In TM specifically. When you when you are active or not active. So I would encourage you to read the paper as it comes out. But we're finding that we use
a technique called transcranial magnetic stimulation to kind of probe the brain and spinal cord as to how healthy those neuronal pathways are. When you take this medication. So, I tell you that more just to offer options of things that you can do that might make everyone you know make you feel a little more like you're on the cutting edge of what's going on with this with transverse myelitis or any other pathology that you may have. You know studies are ongoing. The more you know about them I think the better because then you can make choices on whether you want to be involved or not. You can at least learn what they found out even if you're not involved.

53:08 Yes. Cathy I always direct patients to clinicaltrials.gov Yeah that's good. Which is a great Web site. It lists every clinical trial going on in the country that is recognized by the FDA. And so, if any of these academic institutions like Johns Hopkins we have to go through an institutional review board and as part of that we have to post our study to this clinicaltrials.gov And so you can find studies going on all over the country and in some different parts of the world even depending on their FDA approval and then it will tell you what population they're studying what the intervention is and then they're required to post updates occasionally too. So that's right a big trial so you'll be able to see what kinds of things are coming out and going on. And so that's a great resource. Like Cathy said if even if you don't want to be a part of a study it's great to sort of look at what's going on and what's happening in the community.

54:08 Right. And also the TMA always list of clinical studies and trials that are going on that are related to TM, NMO, ADEM or optic neuritis as well on our Web site. And then we also try and do literature summary. The peer reviewed literature people don't have access to journals. So those are also available on our website as well. It's always exciting and it's there's a lot of opportunities out there as well.

54:36 That's great. So I know we're going to head towards the end of our hour.

54:44 So is there anything that we feel we should have mentioned or have any last thoughts about the whole occupational therapy.

54:56 One day I always tell my patients is that recovery is activity dependent and putting your pants on counts as activity. So sometimes people think oh I need to have somebody else come in and help me with my cares and get me through my morning stuff and feed me and get me dressed all these things so I can go about doing my therapy and I try and shift that focus to like every time you move every time you make an effort to do something that you didn't do yesterday no matter how small that is therapy and that is the activity that we're talking about that is going to change your nervous system. It's not the 30 minutes of exercise that you're doing. It's not that twice a week you come to therapy. It's every day trying something new.

55:40 Right and there's lots of little ways to kind of motivate people to try to stay active right. There's a there's a stuff on your iPhone app on the iPhone that you
can get for free. That can monitor where that iPhone has been. So keep in mind that that's just measuring where the iPhone goes. There's also you know the wrist worn accelerometers like Fitbit that you can wear and you can wear those on your wrist or you can wear them on your ankle or around your chest. And this will this measure of where that thing goes. So if you wear all the time you can have an objective measure of where that have been and if it stays on your body then that's where you've been. Right. So this is a way to sort of monitor I guess I equate it similar to weight loss even if it's just a few steps but you're doing a few steps more all the time or if you a little bit more activity that's progress.

56:32 And that's the kind of thing that you want to kind of help motivate you so that you can stay moving and not just give up and have those couch potato days too many you know too often or too many in a row. I think these kinds of discussions are really important to have to like. I'm glad that the focus was on something like occupational therapy because I think the focus so often is on you know what medication is going to work or how what kind of physical therapy. So relevant with occupational therapy I think doesn't always get the center stage even though our job is really to try to help keep people functional and that's everyone’s goal right. So I appreciate the TMA just having sort of the interest in really focusing on occupational therapy.

57:25 Agreed. I think it's super important to you because you know walking is a really like hot topic right. It's the thing that everybody wants. But what people forget is that if you can’t walk if you can walk it doesn't mean that you're going to be able to do everything else anyway. So a lot of my patients particularly young teenage men come in and they think that if they can walk they'll be able to tie their shoes and put their pants on and brush their teeth and type on the computer and cut their food and that's not necessarily the case. Your therapy really needs to be well-rounded and geared towards the things that are most important to you. And that doesn't have to be walking right.

58:07 I agree. Yet people assume you know when you have problems that your walking is the ultimate goal there is so much more in life. So there is there is a lot more than just that. So yes I appreciate your time very much. You did get to comment that the podcast was very helpful. And that is for you for the information so that from our listeners. Yes. Thank you both very much. And just a reminder to everyone that this will be available on our Web site in our resource library as well. So they both.

58:44 Thank you.

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