Symptom Management Q&A Panel

You can listen to the audio of this talk at: https://youtu.be/aqxD6KCZ57g

Dr. Jonathan Galli: [00:00:00] For the last session, in case you guys weren't involved, we have some email questions that we'll get through. And then we'll try to - I promise we're not ignoring the chat. We're just, like I said, we're trying to get used to this whole virtual thing. So we'll also try to cover some of the chat questions as well.

[00:00:19] I know some of you, some of you guys were taking care of the questions as we, as we went along. And so, I guess I, I'll actually start with, Stephen Tate. That's a great question in the chat. I'll start with that question. "Does an increase severity of the symptom indicate an ongoing recurrence?" And I don't know if either Dr. Poon or Dr. Abbatemarco want to start with this and answer that question? And I'm happy to weigh in as well.

Dr. Jason Poon: [00:00:54] Sure. So I, it depends. Sometimes, more often we think of increasing severity as maybe not necessarily recurrence, but it could be... It depends on what the previous symptoms were. And we think of recurrence of previous symptoms as more of environmental factors, possible infection, sort of what is called pseudo relapse.

[00:01:26] But one of the things about a demyelinating disease though, is that it's reasonable to get reevaluated. And depending on how severe the symptom is, increases in, like, rate increases in severity should be reevaluated.

Dr. Jonathan Galli: [00:01:49] Yeah, and I would, I would echo that. And I will tell you, you know, when I talk with my patients, the simple answer is it depends.

[00:01:58] I oftentimes see in my patients with spinal cord injuries, that the weakness is really the presenting symptom, but in the backend, the pain and the spasticity really kind of transitions over to that. And that's, that's more of, kind of, the course of the disease. So it doesn't always mean that you're necessarily having a recurrence or you're having active inflammation of the spinal cord or things like that.

[00:02:26] Like we touched on last time, a lot of things can flare up the old lesion symptoms. But oftentimes I see a year out, two years out when the neurogenic pain and the spasticity is really more bothersome. Alright. And then, Janet, there was a question, and we talked about this a little bit, but what treatments are recommended for someone who has neurogenic bladder?

[00:02:53] I think you covered that, but if you wouldn't mind maybe kind of, kind of rehashing it briefly for us that would be great.

Janet M. Dean: [00:03:02] So, you know, I think the most important thing is to get a good evaluation. So finding a urologist that can really help you figure out which kind of bladder, you know, you have, whether it's upper motor neuron or lower motor neuron. You also need to make sure that

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your kidneys are safe because if you're having backup of urine into your kidneys, that's dangerous over the long haul.

[00:03:29] And then once you kind of get figured out whether you have an upper motor neuron or a lower motor neuron bladder, then you can figure out how you need to treat that. And I don't know if, you know, with a spastic bladder, you probably need to look at using medications to relax your bladder. And, if you're just... There's a broad spectrum with people with neuroimmune disorders from, as I said, urgency and frequency to needing to have an intermittent cath program.

Dr. Jonathan Galli: [00:04:06] Okay, great, thanks. And I'll tell you, you know, sometimes it's very difficult because, you know, if you have a large enough lesion, you can sometimes have a mixed picture where you have both spasticity, but also bladder flaccidity. You know, a flaccid bladder. I'm not sure flaccidity is a word. And oftentimes, we'll rely on our urology colleagues to help really parse that out.

[00:04:34] At the University of Utah, we're incredibly lucky. We have, we have a urologist, Dr. Lenherr, who I refer to a lot. And she's, she's fantastic at not only helping answer that question, but helping manage. And so, you know, it's, depending on, you know, which one's more severe, that kind of dictates treatment as well.

[00:04:57] Great. There was a really good question here. "I have a seven-year-old granddaughter with transverse myelitis, with subsequent spasticity from the hips to toe. Her doctor wants to do Botox and other doctor wants to do surgery on the tendons. What are our thoughts?" Dr. Poon, or Dr. Abbatemarco, I don't know if you guys wanted to weigh in on this at all.

Dr. Jason Poon: [00:05:25] So I think it does depend a little bit case by case. It's hard to tell basically, from chat, what the case is. But in general, we think of Botox as a trial first, is reasonable. And talking to the PMR docs and surgeons is probably the best way to ask why they want to do surgery first, in this area.

Dr. Justin Abbatemarco: [00:05:59] Just to kind of add on to that topic, and I think it's the same approach for pain management. It's a trial and error sometimes.

[00:06:06] And so it takes some different medications, some different procedures like Botox. But I think we leave surgery as our last resort for all of it, whether it be pain management or spasticity management. But it's going to take on a, kind of a multidisciplinary team to be able to come up with an answer there.

Dr. Jonathan Galli: [00:06:24] Yeah. And I would - go on, Janet.

Janet M. Dean: [00:06:26] So I was going to say, if we don't manage the spasticity, if you do surgery, you may be right back where you started from if we haven't managed the spasticity in the first place. So I think, you know, I always opt with let's figure out meds, Botox, whatever, to manage. And even sometimes the Baclofen pump, if it's severe enough, can reduce the number of surgeries that you have to have.

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Dr. Jonathan Galli: [00:06:53] Yeah, no, that's great. That's, I completely agree with that. And, there's a question for Deb. Years after acute onset of double vision, this person describes: substantial difficulty persists, especially with reading. Their visual acuity is okay when that gets tested, but they are having trouble perceiving a difference between things like "chat" - C H A T - or "apostrophe hat" - H A T. What would be an appropriate way to get help with this?

Deb Nikkila: [00:07:34] Unfortunately, because I personally am currently in the process of obtaining my specialty certification with low vision, but I'm not done with it.

[00:07:50] So I'm afraid that one gets a little too technical beyond what my level of training is right now. What I can say though, is that was not my understanding, though I could be incorrect, that double vision was really a symptom of the optic neuritis. You know, the visual condition associated with neuroimmune disorders. Double vision specifically could be another, you know, occurring disorder or condition happening. I'm not certain that the two correlate.

Dr. Jonathan Galli: [00:08:31] Yeah. No. And that's, and I can tell you, you know, if, if... hopefully this answers your question and it's a very, very good question. You know, if it's a problem specifically related to double vision, you know, if in MOG disorder, you have a brainstem lesion, or even in, you know, neuromyelitis optica, if the lesion goes up and into the brainstem, which is rare, but it can certainly happen, you definitely can have some diplopia. And, generally, I know our neuroophthalmologists here at Moran, what they will generally do is wait until the double vision is stable. And then one of the things they can do is put prisms in a pair of glasses and that kind of refracts things so that it ends up compensating for the double vision.

[00:09:26] Now they don't want to do that early on, obviously. Because if you're going to improve on your own for a little bit of time, they don't want to overcorrect and then have you have double vision because they've over-corrected. So that's one thing to think about is seeing a neuroophthalmologist or even an ophthalmologist about prisms.

[00:09:46] And then, you know, depending on if some of it is more related to how you're perceiving, so if it's more of a brain or a cortical issue, then it's really working more with occupational therapy on that.

[00:10:00] Alrighty. And then, Janet, this is a question I think aimed for you. Can you provide suggestions in increasing sex drive in men? Is Clomid one thing that you might suggest?

Janet M. Dean: [00:10:19] No, that's out of my area of expertise. I could kind of do basics about that. I'm a pediatric nurse practitioner.

Dr. Jonathan Galli: [00:10:26] That's okay.

Janet M. Dean: [00:10:28] That's out of my -

Dr. Jonathan Galli: [00:10:30] No, that's okay. And then, Aaron Danner, you had a question about quads and hip flexors having a lot of spasms. It is hindering walking. And this is a really common, this is a very common problem with spasticity. And actually, in some patients can be more of the problem than the weakness.

[00:10:56] You know, it can be a little bit of both, but certainly, it is something that can get in the way of your ability to walk. Dr. Clardy, it looks like, got onto the chat. But I agree with that. Things like Baclofen, other medications, Tizanidine, can be really, really helpful, especially if it's more diffused. So how we manage this and I think, this, you know, we were talking about the neurogenic pain and the spasticity management, you know, a lot of it is, we use the term trial and error.

[00:11:37] You know, when I talk to my patients, I'll say, you know, it's not quite like we're taking spaghetti, throwing it at a wall and seeing what sticks, but kind of. And it really does depend on how you respond to medication. So oftentimes, something as simple as starting Baclofen scheduled during the day can be really helpful.

[00:11:55] Or some of the other medications, if you're having side effects with Baclofen. The other things to think about though, are, you know, especially if you have more of a focal spasticity, doing injections like Botox, especially if you have one limb that's really involved, those Botox injections can be incredibly helpful to loosen some of those areas of spasticity.

[00:12:20] And then Baclofen pumps are something to think about as well, that I know in our institution, our rehab department, helps to manage those. And it really is just kind of figuring out what works, but also making sure that we don't over treat and run into more problems down the road. Just for instance, you know, some patients with spasticity actually use that to help them pivot and transition from, you know, say their wheelchair over to their bed.

[00:12:48] And if we got rid of some of the spasticity, they would actually have more trouble making that transfer. And so that's something that we have to be aware and are careful about. And you know, it is probably one of the things that takes the longest to really nail down, is symptomatic management, you know?

[00:13:05] I think, Dr. Poon and Dr. Abbatemarco would probably agree here. When we are seeing patients, really, the first thing that we're doing is trying to establish the diagnosis, get you on an immune therapy. Oftentimes that's the easiest part. Especially if we say, oh, this looks like, you know, neuromyelitis optica. Okay, here's your treatment. It's really the symptom management that eventually takes precedence over the next six to 12 months but admittedly can take a long time.

Dr. Jason Poon: [00:13:36] Yeah, I would actually also reiterate what Dr. Clardy has already said, and that is, that really emphasize stretch. And if you're able to bear weight, bearing weight as well, as part of your rehabilitative program, along with a PT, OT, or something like that. Botox is helpful, but we do have to be careful because you don't want to take away the tone that allows you to transfer and stuff like that.

[00:14:06] So everything has to be tested very slowly.

Dr. Jonathan Galli: [00:14:13] I think this is a real... Nancy, your question in the chat is really good. "I've had, previous episodes of optic neuritis and recently developed significant loss of near vision, as opposed to overall visual acuity. Could this be the optic neuritis contributing or is it more aging?"

[00:14:35] Dr. Abbatemarco, if you wanted to weigh in on that a little bit, I'm happy to do so after.

Dr. Justin Abbatemarco: [00:14:40] No, absolutely. It's a common question we get in the clinic. I would say, we always like to rule out each related thing, right, as we get older. And near vision can definitely become impaired. And that is not usually a part of the disease process. And so if, you know, cheaters or glasses are able to correct that, then we wouldn't expect the optic neuritis to be contributing. You know, that being said, it's not...[inaudible] it could definitely be contributing a little bit. But I think going after some of those easy things that are easily correctable, such as the cheaters to help with the near vision, that would be an easy way to approach it. I don't know if you have any other thoughts there.

Deb Nikkila: [00:15:28] Well, if the cheaters aren't providing enough correction for you, that would be an area that is still eligible and reasonable for seeking low vision rehabilitation. And that's where that magnification training comes into play.

Dr. Jonathan Galli: [00:15:51] Yeah, I would echo all of that. Sheri Castle has a question. Any guidance on poor sleep? I'm just, sorry, I'm just reading this real quick. So, just kind of, I guess we can touch on sleep in general in many of these conditions. That's, it's definitely a area that can be incredibly bothersome for patients. I mean, you know, the general public regardless, yeah, a lot of people have sleeping issues and then you tack on that, some of these rare conditions that have these residual symptoms. And so, with optimizing sleep, there's really, there's really a couple of things that we absolutely have to take into account. So one of them is what is keeping you awake. And so, you know, trying to answer your question here.

[00:16:53] So if you're having a lot of pain, so if you have a lot of neurogenic pain at night, that's oftentimes when things will flare up. We will really gear your treatment towards treating the neurogenic pain. Right? Like, so starting a lot of neurogenic pain agents, you know, or starting a neurogenic pain agent, especially at night, can be very helpful. A lot of them have the side effects of making you tired, which in that case isn't so bad. You know, Amitriptyline and Nortriptyline are two medications I will often use because they make you sleepy and they help with nerve pain. Although there are a lot of different medications that can be helpful.

[00:17:34] You know, some of the questions, about, and I know in your question, you don't have abnormal leg movements or obstructive sleep apnea, but those are things that are certainly worth looking for. You know, I think it's always a good idea to rule out obstructive sleep apnea, especially because - or sleep apnea in general - because if you have a central nervous system lesion within the brain, you're actually at risk for what's called Central Sleep Apnea.

[00:18:00] And that's an important thing to make sure we don't miss. As well as Restless Leg Syndrome and things like that, periodic limb movements at night, because those are things that definitely can happen with spinal cord lesions. And if all of those are ruled out and you're having just multiple arousals, that may just be, you know, again, going back to, is it pain, that's waking you up?

[00:18:19] Is it having to wake up at night, and use the bathroom? That can definitely be a piece of it and making sure that you kind of manage your nighttime urinary and bowel routine to make sure that that's not something that's causing symptoms. And spasticity can definitely be a problem that, either A) wakes people up, or makes it hard so, you know, you can't even roll over, you know. I, we

see this in patients a lot where it's, you know, if I'm lying on my shoulder a little bit funky and my arm's starting to go numb, I can just roll over in bed. But if you have significant spasticity, that may be that much harder. Or if you have significant weakness, that makes it that much harder.

[00:19:01] And so it really is sitting down and figuring out what is it that's waking you up. And again, that can be, that can be tricky and that, I would recommend talking with your provider and really, on your end, kind of, keeping a log almost of what, what symptoms or what you're experiencing at night.

[00:19:21] And if it's really none of that, if it's just, I'm just waking up, then it's, then it just becomes, you know, do we start you on a sleeping medication, like Trazodone? Could certainly use Amitriptyline, things like that. So, those, I hope that answered your question a little bit.

[00:19:42] And I think, Natasha, Dr. Abbatemarco's talk should be available, I believe, that has a lot of the neuropathic pain medications on them. So hopefully they can set you guys, set you up with that. And then, Carolyn Davis, the question: is Baclofen the only muscle relaxer that's used in a pump? To my knowledge, it's the only one we use, is a Baclofen pump. Jan, is that correct?

Janet M. Dean: [00:20:16] At different points over the last 25 years, they've tried different medications and pumps, but I'm pretty sure that it's not recommended to put anything besides Baclofen in a pump.

Dr. Jonathan Galli: [00:20:31] Yeah. Okay. That was my understanding too. And Dr. Poon, you agree there too? I see you nodding.

Dr. Jason Poon: [00:20:36] Yeah. There's been many medications tried, but by and far it's not worth trying.

Dr. Jonathan Galli: [00:20:45] And then, Jeannie, you started Baclofen, you've been on a low dose since. I would definitely talk with your provider. Generally, we start these medications out. Both neurogenic pain medications and medications for spasticity really should be started at a lower dose. Even to the point where it's maybe not even effective. And the reason is, you know, Baclofen for spasticity or Gabapentin is a very common neurogenic pain agent. You know, the maximum dose of Gabapentin for example, is 1200 milligrams, three times a day. If I started most people on that, they would just sleep. So we usually start at pretty low doses and kind of ramp them up as tolerated. And that can take some time, but I definitely would talk to your provider about that for sure. I think it's, it's a very important thing to make sure that you're not just started on medications, but kind of titrated to the appropriate dose.

[00:21:50] And then, I'm just skimming. It looks like if they're going to make the slides with the proper spelling of the medications. And I'm just making sure we don't... if you guys have more questions, feel free to pop them in. We've got a few more minutes. Looks like Dr. Clardy is cleaning out the chat for us.

[00:22:22] So Christine, you tried Baclofen at night twice. Both times it made it worse.

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[00:22:33] I have seen patients, and Dr. Poon and Dr. Abbatemarco, I'm sure you can weigh in on this. Sometimes patients for whatever reason do seem to know, kind of almost have an opposite effect with the medications. If that's the case, I usually, I don't have a great explanation for it per se. But that said, I think it's very reasonable to switch you to a different medication or strategy. I don't know, Dr. Poon, if you have any thoughts?

Dr. Jason Poon: [00:23:03] So Steven Tase is asking, do other things kind of more off the counter help? So magnesium is one of them that we often ask people to try. And it doesn't have a lot of significant side effects. It's really hard to overdose on magnesium. It can possibly lead to [inaudible] or diarrhea depending on the person. And then another thing that Dr. Rose likes to do is quinine or quinine water. And these are just things that you can try.

Dr. Jonathan Galli: [00:23:46] Jeannie Matthews regarding: "I'm on a low dose of Gabapentin. They've discussed increasing this as needed. The concern is that taking too much of the medication will slow your improvement." In general, I don't see these medications as anything that will slow down your improvement overall. They're not going to, you know, slow any of the physical improvement, weakness, things like that from coming back. And in general, I think, you know, one thing to just be cognizant of and think about is, you also don't want your pain and your spasticity to get in the way of your improvement.

[00:24:24] You know, if you can't participate with rehab because frankly it just hurts too much or you're too tight, that may get in the way of your progress. And, the most important piece from an improval standpoint is that really pushing through and doing physical therapy and working with rehab, and that's the most important piece of regaining as much function as you can.

[00:24:50] All right. I think we have time for... Oh, sorry. There's a question about optic neuritis and nerve pain. I'm sorry, I might've skipped over it in the email or in the chat. Dr. Abbatemarco, if you wanted to weigh in on that, that'd be great.

Dr. Justin Abbatemarco: [00:25:09] So eye pain [inaudible]. Goes away pretty quickly with treatment with steroids or other kind of therapies such as PLEX. It can reoccur. So common stressors, and I use that broadly, can bring that back. Infections that we talked about. Heat.

[00:25:31] So people can feel that discomfort around that eye. It does not usually imply that there is new damage occurring or it's recurrent optic neuritis, especially if it goes away quickly. But if those symptoms are persistent for hours to days, you definitely should reach out to your provider. But in general, the pain around optic neuritis should go away and only re-emerge during times of quote, unquote stressors, like we talked about.

Dr. Jonathan Galli: [00:25:57] Great. So we're, we're I think at the mark to, to move us on. I want to make sure you guys have a chance to meet with our sponsors and exhibitors.

[00:26:09] And so I'll have you guys moved along to the expo session right now. And if you look to the left, it's on the bar there. And we'll, we'll plan to have you guys meet with them. And again, apologies, a lot of great questions. We could probably be here for hours and still not get to everybody. So we appreciate it, guys. Thank you.

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