

# Managing Spasticity with a Baclofen Pump

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**Dr. GG deFiebre:** 00:00 Hi, everyone, and welcome to the SRNA's "Ask the Expert" podcast series. This podcast is titled "Managing Spasticity with a Baclofen Pump." My name is GG deFiebre, and I moderated this podcast. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at [wearesrna.org](http://wearesrna.org). Our "Ask the Expert" podcast series is sponsored in part by Horizon Therapeutics, Alexion - AstraZeneca Rare Disease, and Genentech. Horizon is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare autoimmune and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Horizon believes science and compassion must work together to transform lives.

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For this podcast, we are pleased to be joined by Dr. Miguel Escalón. Dr. Escalón is the Vice Chair of the Department of Rehabilitation and Human Performance at Mount Sinai in New York City. He came to the Icahn School of Medicine at Mount Sinai in 2013 and has served as Director of Critical Care Rehabilitation since 2014, and as the Residency Program Director for the PM&R residency since 2017. He also serves as the Director of Brain Injury Medicine at Mount Sinai and is the Fellowship Director for the Brain Injury Medicine Fellowship. He's an Associate Professor in the Department of Rehabilitation and Human Performance and the Department of Medical Education at the Icahn School of Medicine at Mount Sinai. Dr. Escalón focuses on neurorehabilitation of any disease that affects the central nervous system, the brain and spinal cord. He's an expert in spasticity management, including intrathecal pump management and botulinum toxin injections. Welcome, Dr. Escalón.

Thanks for joining me today to talk about the baclofen pump. To start, do you mind just giving a brief overview of what spasticity is, what tone is, and what causes these issues in people with rare neuroimmune disorders or who have issues with the spinal cord?

**Dr. Miguel Escalón:** 02:47 Yes, thanks for having me. Great question. So, spasticity is hyperreflexia – let me try and explain as best I can. We all have reflexes, and our body is built that way. Usually, we're built that way or made that way, so to speak, to protect ourselves. So, if you put your hand on a hot stove, it pulls back.

Or if you're walking down the street and you go to step on a nail, you could imagine that your leg would draw back, started to feel the pokiness of the nail. But we don't think about it as our brain always has final say over reflexes. So, you could put your head in boiling water, say, to save something precious, or if you were walking down the street and you went to step on that nail and you were holding quadruplets and you were worried that by pulling back, you could lose balance and drop all the kids, then your body might walk through the nail knowing that it would hurt you. So, what happens after any insult to the central nervous system?

So, that could be the things mentioned or even a stroke or anything else, that brain cortical control over the reflexes is lost, in whole or in part. Sometimes that gets better with time, sometimes it doesn't change, but it gets affected to some degree. And that means all the reflexes that our brain is constantly telling "no" to start to turn on and get to run amok. So, that's what becomes spasticity. And it can present in different ways. And we as doctors do a really bad job because we use multiple different words to describe, from a patient's perspective, the same thing, even though like in a textbook, they might technically be a little different that ultimately the same thing to you. So, you might hear the word tone or spasticity or tightness or stiffness, but they're all kind of the same thing. I think the important thing to get across as a doctor or a physical therapist, who you're seeing is, are you having a component of jumping to the spasms or tightness? Or is it just a stiffness that kind of locks in place and you can't get rid of it? Or is it some kind of combo?

**Dr. GG deFiebre:** 05:14 Great, thank you for that overview. And so, how long does it typically develop? Take for spasticity to develop if it's going to happen. So, someone might, for example, get diagnosed with transverse myelitis or neuromyelitis optica or one of the other rare neuroimmune disorders and they present to the hospital, do they typically see spasticity right away? Or does it take some time to develop?

**Dr. Miguel Escalón:** 05:37 Yes, that's also a really good question. It's a little bit different depending on the diagnosis. So, for NMO, often there's eye involvement. It's in the name there. But some of the first symptoms might actually be related to spasticity. Now in hindsight, you might think, "Well, oh, yes, I was tripping over myself a few years ago and I didn't really take it seriously." But some of the first presenting symptoms to a physician might be related to spasticity, and sometimes tripping over your foot is one of those related to spasms, making your ankle point down. That's in contrast to something like transverse myelitis, which also can kind of present differently, but classically presents with total flaccidity or softness in the leg. So, your legs become like Jell-O, and they don't move, and you can't move them, and they have no spasm, no reflexes. And then over the course of weeks to months, you could develop, depending on how you're healing, you could develop a spasm. So, in general, weeks to months, I would say, although NMO and some other processes can be a little bit slower. Not always right away, if you could actually pinpoint like the minute when something started to happen, usually spasticity doesn't start until – the earliest would be in the setting of like a traumatic spinal cord injury or something like that on the order of few days or weeks.

**Dr. GG deFiebre:** 07:07 Got it. And then, so once someone has their spasticity diagnosed, how is it treated? What is kind of the first-line treatment and then second-line? I know, we'll be talking in more depth about the baclofen pump. But if you can kind of walk us through what the options are and kind of what the process is for getting from one option to the other?

**Dr. Miguel Escalón:** 07:29 Sure. So, a couple things if you'll allow me to indulge. One is spasticity in and of itself is not bad. So, treating it really revolves around whether it's affecting your life. So, I've had patients that where spasticity allows them to stand up, or other patients that want to have a little bit of spasm, because it keeps the muscle tone in their legs, and it's thought to help prevent blood clots and things like that. But if the spasms are preventing you from progressing with therapies, or they're really painful, or they're keeping you up at night, or they're making transferring from your wheelchair to the bed really dangerous, then they should

be treated. And the other thing to keep in mind is spasticity can take a little bit of time to level off, or where certain diagnoses like NMO or MS can change over time, become more or less or kind of go up and down.

So, when I'm going to mention treatments in a second, it's going to be under the assumption that a person has kind of reached a steady state of spasticity and that we're starting from kind of least invasive to most invasive. So, step one usually is stretching. You teach someone how to stretch and hopefully they can stretch themselves or someone can help them stretch. If that's not enough, then on top of that, we might add oral medications, oral baclofen, tizanidine, there's a whole bunch of different kinds. If the oral medications and the stretching don't work, we might add on top of that, or in lieu of the oral meds, different injections. You might hear there are botulinum toxins, you might hear brand names like Botox or Xeomin.

There are also injections like phenol. In the end, from a consumer or a patient perspective, they're all meant to do the same thing, which is kind of turn the spasms down without turning the muscle completely off. And then when those things don't work, you might go – or if you have side effects to these things, you can't tolerate them, then you might go to something like a baclofen pump. Historically, there used to also be other really aggressive surgeries like cutting of nerves and cutting them the spinal cord and all these things which we don't do anymore, and I would never suggest. So, usually kind of that last thing that we get to is a baclofen pump when we take the order of operations kind of classically. We don't have to follow it that way, but just to give an example.

**Dr. GG deFiebre:** 10:08 Great. Yes, thank you. And then what is a baclofen pump? How does it work? And if you could just talk a little bit, we do often get questions on if it has any impact on – if someone has neurogenic bladder, that's kind of a spastic bladder or bowel function as well.

**Dr. Miguel Escalón:** 10:26 First and foremost, just like with anything, medications or any other devices, there are different brands. So, I happen to have a sample of a pump here. So, you can see it's about the size of a hockey puck. And what you could see here is I'm going to turn off my blur for a second. I think that'll help. So, what you can see here is there's a circular part, and it's relatively thick. I mean, this is a certain brand, but they're all about this thick. So, that's about an inch thick. And there's this little, I don't know if you can see that, like a little plastic film there. So, this metal part is basically almost totally empty and what it's filled with is medication. And the way it's filled is through this little plastic port, which I think we'll get into a bit more later.

But what happens is, basically, this pump is filled with medicine and inside, there's a tiny little motor. And this part, sort of like appendage or wing is connected to a tube. So, the pump lives in your abdomen, kind of in the lower part under your belly button on the left or right. And then it's connected to a tube that goes around the side of your flank and goes into your spinal cord – not into your spinal cord, into your spinal canal and delivers medication, in this case, baclofen. So, that's what a pump is and kind of how it works. The pump can be set to deliver a continuous dose. So, it can kind of deliver like the same dose every hour over the course of the day. Or it can be changed to give you more in the morning or more at night, depending on how your spasticity changes. It's easily adjusted. In the office, it takes like two minutes to adjust the dose. So, if winter's coming and you're more spastic in the winter, it can be turned up super easy. It's a surgical procedure, so you have to undergo anesthesia to have the pump placed. It does go under the skin. Did I answer everything?

**Dr. GG deFiebre:** 12:38 Yes, that was great. I've actually never seen a pump before outside. So, it's very interesting as someone who wants to be able to actually see it. It's a lot thicker than I thought it would be.

**Dr. Miguel Escalón:** 12:50 Yes, I think this is a different brand, I think. So, this is Prometra. There's also Medtronic. Medtronic is by far the most kind of common and popular. The Prometra is a little thicker. It's a

little bit, like the diameter is a little bit smaller. So, the Medtronic is just the tiniest bit wider and thinner. The Medtronic also comes in two sizes, 20 cc, 20 milliliters, and 40. So, certainly, the larger the pump, the longer the medicine will last.

**Dr. GG deFiebre:** 13:21 Right. And are the smaller pumps typically used in, for example, pediatric cases or smaller people? Or how do you kind of determine which pump someone might get?

**Dr. Miguel Escalón:** 13:30 Yes, usually peds definitely have a smaller pump. And they have to grow with it, that's a little complicated because if, say, you're a teenager and you get diagnosed with something and you're still growing, it's a little complicated. You might have to have repeated kind of adjustments of the tube or the catheter, because they'll put it in a place and then you'll grow and then they'll have to like snake it up, again. But the pump size is usually smaller, smaller size for kids. The size in adults really has to do with your dose. So, the higher the dose you have, if once you cross a certain threshold, we'll put a larger pump in, so you don't have to come so often. I think an ideal goal for refill is between every three to six months. So, if you're coming every like month or six weeks, then there's certainly a consideration for increasing the size of that pump or increasing the concentration of medicine, but there's only so much we can do then.

**Dr. GG deFiebre:** 14:29 Okay, thanks. And then in terms of how it works, so you mentioned that there's a tube that runs from the pump around your abdomen and then into the kind of bathes the spinal cord with the medicine, is that correct? Do you want to talk about why that works or how that's kind of different than taking it as an oral medication?

**Dr. Miguel Escalón:** 14:50 Yes, so the medication, again, that's going in the pump is baclofen. So, if you're not familiar with it, it acts on GABA receptors in your brain. But in order to do that, it has to go from, when you take the pill, it's got to go in your stomach and be absorbed and then cross your blood-brain barrier, which is hard to cross. Our bodies are made that way because, let's say, we got the cold or flu or whatever, our body doesn't normally want those viruses to get into our brain or spinal cord. So, the blood-brain barrier is purposefully made hard to cross, and that also extends to medications or any substances, really. Some are easier to cross and that's why we can get drunk, for example.

In the case of baclofen, the majority of the medication that you ingest stays outside the blood-brain barrier, so there tend to be other side effects that can happen. And so, baclofen, some people tolerate it pretty well, other people don't. People can get really tired. People can have cognitive changes. People can have liver issues, kidney issues, or different things.

And so, the idea here is if somebody was responding to oral baclofen, but they were having a side effect, or the doses getting like really high, and it just makes sense that you're taking 50 pills a day and it's just taking over your whole life, then we can, via the pump, give you hundreds of times lower doses of baclofen, because it's going straight, we don't have to account for all that extra, that's not actually going to make it into the spinal cord. We can just give that little bit of medicine right in and around the spinal cord, spinal canal. And usually, we can get a much stronger or better effect or bang for our buck in that way. And it's usually pretty well tolerated in terms of side effects. We don't see a lot of medication side effects from the baclofen pump.

**Dr. GG deFiebre:** 17:06 Right. And then, so obviously, it does have an impact on spasticity in most cases. Does it have an impact on someone's bladder or bowel function, for example, if they might have spastic bladder issues?

**Dr. Miguel Escalón:** 17:19 Yes, it could. Again, that will depend a little bit on the dosing, but the short answer is yes. So, if I put a pump in you, well, if the surgeon puts a pump in you and I turn the dose way, way, way

up, so that your legs are very nice and loose, it will affect your bowel and your bladder potentially as well, if they're spastic. So, say, you're someone that voids or urinates into a diaper or a condom catheter, and you rely on the spasticity to do that, the pump could affect that. Now, I do have a lot of patients that have the pump and are able to still urinate. It just has to be something that you're watching, and you have to find that kind of middle ground with that. But it's something to consider. And it's a good question.

**Dr. GG deFiebre:** 18:08 Okay. And so, then when – so we talked about kind of the steps that you take to start with these oral medications, maybe use some of these injections like Botox. So, when do you consider using a baclofen pump for a patient typically?

**Dr. Miguel Escalón:** 18:23 Yes, so one way might be, we've gone through that whole order of operations, and everything hasn't worked. And then we would say, so before anyone gets a pump, we would do the baclofen trial. So, which is a glorified epidural or a lumbar puncture. So, same as somebody would get like, if they were getting a C-section if they were pregnant. So, it's a lumbar puncture, I'm sure many people listening to this are familiar with what a lumbar puncture is. So, instead of taking a lot of CSFs out for all kinds of crazy tests, we actually put a little bit of baclofen in, and we monitor you for two to four hours.

And basically, it's a test run just to make sure that the baclofen will work for you. Because we don't want to put the pump in without knowing for sure that the medicine is going to do what it's supposed to. So, assuming the trial goes well, and the person is interested, then you meet with the neurosurgeon and the implementation happens and all of that. Regarding the actual process of deciding when to do it, a lot of times I'll leave it up to the patient. So, most of what I will do in a first appointment, if I think somebody has – somebody comes in and they're spastic just in their right hand, I'm probably not going to mention the pump. But if I can see that somebody has spasticity in their leg – and this is another point actually, as an aside. Depending on how high up your spine the catheter is threaded, you may or may not get relief in your upper extremities.

And as much as the pump companies will tell you that gravity has nothing to do with it, I have a lot of patients that feel like when they're laying flat on their back, the medicine gets more to their upper bodies. And then when they sit up and throughout the day, it kind of goes away and their upper body is a little more spastic. So, something to consider. But anyway, if I see that somebody has more systemic spasms, maybe a couple of limbs, or more than just a joint, and I foresee that there's even a 1% chance that I might offer them a pump one day, I just kind of put it all out on the table day one. And maybe that's the wrong thing to do, it might be a little overwhelming. But just to say, like, there are a lot of options, so don't worry, like, we can solve this somehow, even if it's not the first thing we try. Usually after we tried oral medications, I have a sense whether you have more spasms, then I can inject with Botox, to use an example. So, there's only so much I can give you safely. Too much Botox, or phenol, or Xeomin, or anything could be, in extreme cases, deadly. So, you don't want to risk that.

And I'm happy to push the envelope as much as anyone else, but there is a limit. So based on how you've responded to the pills, I tend to have a decent guess as to whether or not I have enough Botox to give you to solve your problem. And most of the time, I'll say, I think you should watch this video or consider the pump and just think about it. And I'll drop hints that way. But I would say 9 times out of 10 patients want to at least try the injections once. So, I usually will do that just for people because the pump is a commitment. It's something that lives in your body for a long time.

But I would say the flip side of that is if someone were more willing to get a pump sooner, then we could help them sooner, and we wouldn't have to kind of – there are times I've gone through a year, 18 months of trying to, to kind of prove to someone that the pump is the only option. Or if we had done it to begin with, that's another year that where they could have been ahead of the game in some aspects.

**Dr. GG deFiebre:** 22:22 Right, yes, just as my personal, I got my pump nine months after my diagnosis of transverse myelitis, just because none of the options worked. So, it's good to hear that there's kind of variability there in terms of when people are offered that. So, what happens during the surgery and what does the recovery look like?

**Dr. Miguel Escalón:** 22:41 Right, so during the surgery, it's a day procedure, technically, but usually you'll stay overnight, one night, unless, God forbid, something doesn't go as expected. But what happens is they make an incision in your lower abdomen, kind of like where an appendectomy used to be or a little bit lower. Nowadays, they don't do the surgeries that same way, but you'll have a scar probably a few inches, three inches, four inches, big enough for the pump to fit through. And what they'll do is, they'll take your abdominal wall muscles and build a little pouch, so the pump doesn't move and shake around. So, they'll actually kind of carve out a pouch with the muscles and then they'll kind of fit the pump in there. And then they will put the tube in, and then kind of thread what they can from that angle kind of around your flank. And then you'll have another incision next to, but not on your spine, where they will find the catheter, pull it, and then thread it into the spinal canal.

In that moment, what they'll do is once that's all done, they will test a little bit of the pump to make sure it's running, and the fluid is actually coming through. Then they'll fill it and they'll set it to whatever dose the doctor that asked them to put the pump in suggests. And then they stitch you up and you go back to your room. You wake up from the anesthesia, the next day you're probably pretty sore. One thing that is – so, a lot of people will go home that next day, especially if they've been living at home already. But often there's an option with a pump to go to acute rehabilitation. So, something to consider.

Some people don't want to be hospitalized, but the pump gives you a change in status. So, if you were to say from a medical – so there are a couple things you need for acute rehab. One, a reason to see a doctor every day. You just had surgery; you need pain management. Somebody needs to adjust the pump dosing to optimize it. And two, it's possible that you have new functional goals now that your spasms will be better controlled. So, there are very few times in a person's life where they can kind of sneak back into acute rehab, even if they've already had it, after a pump placement is one. So, it's something to definitely consider and talk about beforehand. Because there's no other time you get as much therapy unless you're paying out of pocket.

**Dr. GG deFiebre:** 25:17 Right, for sure. And so, what are the potential risks of the surgery? I know there's obviously really general risks with surgery. We've heard things like people getting headaches or something after pump placement. Do you mind talking a little bit about that?

**Dr. Miguel Escalón:** 25:31 Yes, the headaches are relatively common, maybe one in four, one in five after the pump trial, which is just a lumbar puncture. If you've had a lumbar puncture, they make you lay flat for a while after. The reason for that is the hole that's made by the needle, if that doesn't close up quickly and the CSF keeps draining out, it gives you kind of like a dehydration, hangover-type headache. And the same can happen with surgery, in theory, if for some reason that it's not stitched up right or you lost more CSF than you thought you would, you could get a headache after the pump placement.

With any kind of anesthesia, there's the risks of anesthesia. Anytime someone puts anything inside your body, needle or knife or anything, there's risk of infection. There's certainly pain that comes with surgery, you might say, "Well, I don't feel pain in that part of my body," but your body might still feel pain. So, if you have dysautonomia or dysreflexia or different things like that, you're at higher risk of that within a couple of days following the surgery. So, you might need pain medications, even though you're not actually feeling pain.

And there's risks that come peripherally, like you might get a Foley placed as part of the surgery and so you might be at risk of a urinary tract infection, or if you need a bowel routine, that can be thrown off with the anesthesia. Plus, the nursing staff that's never done that before for anybody.

There is risk to the pump itself, although like, I could probably count on one hand the number of times I've heard of the pump itself failing. The pumps usually don't fail, it'd be like your computer just not working, like the motor in the pump. But what I have seen happen a few times is the catheter can come loose or become kinked. And in those cases, the correction is surgical. So, I would say, and I think we're going to get into withdrawal a little bit more later. And so, there's other considerations. But in terms of the surgery itself, probably the biggest ones are the ones mentioned. Pain, bruising, bleeding, infection, so those are the big ones.

**Dr. GG deFiebre:** 28:01 Okay. And then what happens after the pump is placed? So, does someone start obviously at a dose? Do you then kind of slowly increase it over time? What's involved with the maintenance of the pump and getting refills?

**Dr. Miguel Escalón:** 28:13 Yes, so if you are, say, you're at Mount Sinai, which is where I work, and you get the pump placed. Then I'll see you that next day and examine you and we have to make sure the anesthesia is worn off because the anesthesia will take the spasms away for a bit. And then we just check and see if the spasms are still elevated, we turn the pump up right then and there and I check you every day. And we can adjust the pump every day. We just have to watch you.

So, the time that you're in the hospital, it can be adjusted pretty frequently every day, every other day. Once you go home, I think probably on the most frequent end, the doctor might be able to see you like once a week for adjustment. If you have somebody that is particularly busy or doesn't have that much outpatient time, you might be talking about once a month.

So, you can get this kind of hurry up and wait effect. And so, if you're taking oral baclofen beforehand, odds are you're going to stay on that for at least days to weeks after the surgery. So don't expect to get a pump placed and then come off your pills. And in fact, I wouldn't suggest that because it could be dangerous to just stop your pills cold turkey. But you'll continue those and then you will slowly come down on the pills as we go up on the pump.

And I mean, in a perfect scenario, you're going to be off the pills and at a good dose in about a month. And probably what happens to most people, I would say it's like three to six, unless you really need a low dose, in which case you'd be at a good dose right away. We'll start you at a low dose. We're not going to start you at a super high dose, because if you overdose, an overdose of baclofen will affect your breathing, which we certainly don't want to do.

**Dr. GG deFiebre:** 30:10 Yes, for sure. So, you talked a bit about how it's refilled through that port when you showed the actual pump. So, do you mind just talking about how it's refilled? Is it done through a needle or what is that process? And then how often does it typically need to be refilled?

**Dr. Miguel Escalón:** 30:27 Yes, so you come into the office, and you can transfer onto the bed, or if you have a power wheelchair, you can recline. And basically, the skin over the pump is exposed, so the bottom part of your abdomen there. The procedure has to be sterile. So, you have to make sure your doctor cleans you off with Betadine or some other ChlorPrep, the same they'd use before surgery, and that they put on sterile gloves, because any infection of the pump goes straight to your spine, which you don't want, because

they're all connected. So, it's done in a sterile fashion. So, when somebody is cleaning you and they're about to do the procedure, you can't let your hand get in the way or anything. So, the actual procedure is done with a needle. And it doesn't take very long.

Usually, the pump is pretty close to the surface of the skin, so it's easy for me to feel. And I feel the outline of the pump that I know right in the middle is where the port is. And the needle goes in. I take out the old medication and put in the new medication. The reason that's done is because the old medicine can expire. And so instead of just keeping it in, I take it out and put in whole new meds. And then I take a programmer, which I don't have an example of, but kind of looks like a cell phone or an iPad usually. And I tell the pump that I have refilled it so that it knows because otherwise it will alarm and tell you that it's empty and it'll be super annoying. That's basically it. So, there's some interrogation of the pump to see where it's at, or adjust dose and update dosing, and then the needle procedure. I'd say, if somebody came into my office and there was zero chit chat, and we just got straight to business, this would be like a 10-minute thing or less.

**Dr. GG deFiebre:** 32:15 Okay. You said typically we will come in like every three to six months, that's kind of ideal for that, the refills?

**Dr. Miguel Escalón:** 32:21 Yes, that's our goal. We do have some patients that come in every month or six weeks, just because their dose is pretty high. And we try not to put anybody through a surgery until they need to adjust the pump. But we do have some people with big pumps that come in every six weeks or two months, their dose is just that high. But the majority of people, three to six months. And even – there are some patients where the medicine can last even longer, but we don't let it sit in the pump more than six months for fear that it could kind of expire. So, six months, seven months, something like that, but it's all just based on your dosing. So, I would say the average is three to four months.

**Dr. GG deFiebre:** 33:02 Okay. And then what are some of the risks of the pump malfunctioning? So, I know baclofen withdrawal is a thing that can happen or if the catheter needs to be replaced.

**Dr. Miguel Escalón:** 33:11 Yes. So, baclofen withdrawal in extreme cases can be deadly. And so, it's something serious. So, when you think about getting a pump, it's really like a marriage. So, you have to – as mad as you are at the pump or whatever, you have to get it filled because not filling it, you'll get very sick at minimum and in a worst-case scenario, you could die. This is true also of oral baclofen if you're at very high doses. At low doses, you'll feel really uncomfortable. And so, you'll start to see an odd kind of – I guess, I'll get into how things can malfunction. But the first kind of sign people see is usually an increase in spasticity. And sometimes people will, they'll wonder, "Well, why is this happening? Everything's been fine. I'm not due for my refill for another couple months." So it can be that. People will complain of itching.

And then, often people will get a little confused or irritated or in the more advanced stages can even hallucinate. So, the mnemonic that we use as physicians – what we call the pump is an intrathecal pump, and then we use it for intrathecal baclofen, so that's ITB. So, the mnemonic we would use is "itchy, twitchy, and bitchy" to kind of try and remember and then teach the residents and med students how to look out for it. If you are having that kind of increased spasm and you're itchy, don't wait, call right away, get ahold of somebody. It's better to take care of that sooner so that you don't have to be admitted to the hospital. Because if you wait, you will be admitted, and your blood pressure could shoot really high, your heart rate could shoot really high, you can get a fever, even without an infection. And those are the things that really are dangerous.

We've seen people have strokes and heart attacks from their blood pressure getting so high. Thankfully, this is pretty rare. But the most common reason I've seen it happen is some issue with the catheter. So, the catheter gets kinked or dislodged, right? Somebody, I don't know, goes swimming and they try like a different



stroke or something and then the kind of like the movement or any host of things can happen. I've never seen the battery fail prematurely. But I guess it's a theoretic possibility, like with any battery. Usually when the battery life is about a year out, we'll start the process of replacement, so we don't wait until it's like a month out. I haven't seen an issue with the pump itself really, except maybe once. And it wasn't my patient. It's just another patient in the Sinai system that I saw.

So thankfully, the pump itself usually is not the problem. Sometimes there can be a user error on like the doctor side. I've never, knock on wood, I've never had a patient live through this that I know of, at least where I would miss. And so, when I go to refill your pump, I would put the medicine in the wrong place and so it wouldn't actually go in your pump. So those would be things. And in terms of treatment, this is important because a lot of emergency rooms don't actually know what to do. So, if you contact like Medtronic or Prometra or whatever your pump manufacturer is, they will send you like little cards that you can put in your wallet to give to emergency room doctor to kind of explain to them that you have a pump and what it is and how to treat it. But the immediate treatment is actually benzodiazepine for somebody that's in withdrawal. That would be something like Xanax or Ativan, and that will calm the symptoms. So, the treatment is not baclofen.

So, if you have a baclofen pump and it stops working, the treatment is not oral baclofen, it's not enough. So, the treatment is Ativan, usually through the IV, or Xanax, something like that. Once you're a little more stable, then the question really is, why did the pump – what's going on? Oftentimes, the correction has to be – unless the doctor just didn't fill the pump in the right way – so one of the things that should happen in the emergency room or if you go to the doctor's office is to have that person access the pump with a needle, pull back to make sure there's medicine in the pump. If there's medicine in the pump, then the problem is either the pump itself or the catheter, because the pump is not empty. Then they should also interrogate the pump with a machine. The interrogator machine will tell you if the motor has stalled. So, what it will tell you is everything's working fine, which we know it's not because you're withdrawing, or the motor has stalled. If the motor has stalled, then the pump has to be replaced. If it says everything's working fine, then usually it's a catheter issue.

And so, at that point, a lot of different things can happen to try and prove to the surgeons that what's going on is going on. Sometimes that involves CT scans, sometimes X-rays, sometimes accessing this part of the pump, which is a side port, which goes straight to the catheter, and so seeing if I can draw CSF from the catheter. If I can't, then the catheter is clearly not where it's supposed to be. So, there are different things that can be done to kind of – but a surgeon certainly wants to know 100% before they go in to replace the pump or the catheter or both. Hopefully that helps answer your question.

**Dr. GG deFiebre:** 39:01 That was great. So, are there things that someone shouldn't do if they have a pump? Like, go in a hot tub or can they get MRIs?

**Dr. Miguel Escalón:** 39:11 You can get an MRI. A lot of places still are confused about that. So, I've had patients need to get a letter or call, I've had to call radiologists. The pumps automatically turn off when you're in the MRI machine and they automatically turn on when you come out. But it's good practice to let your doctor, your rehab doctor or neurologist, whoever is filling your pump, know that you're getting the MRI, and just to go by their office real quick and have the pump interrogated to make sure that it's working. Because there is the theoretical chance that it will turn off and not turn back on. And then we have to use the interrogator to manually turn it back on.

I mean, hot tubs, whatever, I think in moderation, you shouldn't put yourself in a position where you could damage the pump, right? So, you probably shouldn't do MMA and you should think twice about wheelchair rugby and things like that. Although I have patients that do it, you just have to understand those risks. A

hot tub? I don't know, I try to be reasonable. So, if you're going to be – here's what I would say about a hot tub. You should really think – what you should really be worried about getting into a hot tub is whether you have sensory deficits and think about burning your skin. If the hot tub is cool enough that you're not worried about burning your skin, then you could get in with the pump. That's what I would say. In terms of flying, it's okay with a pump. I guess it could, depending on what country you're in, or where you're traveling, it could look weird on the X-ray machine.

So, I've never had an issue, but you could get a letter from your doc for that. I think hyperbaric oxygen chambers are not advised with the pump because the different changes in pressure could affect and crush the pump in theory. I wouldn't do any – once you have the pump, you shouldn't get a tattoo over where it is. If you already have a tattoo in that area, there's a chance that you'll get an incision through it. But you shouldn't get a tattoo over where the pump is. Those are the only ones I can think of kind of offhand. Don't use your pump to inject other things in, you could die. So, it's not like, "Hey, I'm having a great time. I just went clubbing, I'm gonna like inject some ecstasy in my pump." Don't do that. Ingest ecstasy like everyone else.

**Dr. GG deFiebre:** 41:47 Nice. Well, relatedly, are there other medications that can be used in the pump by a trained healthcare provider? Can you mix baclofen with other medications for someone?

**Dr. Miguel Escalón:** 42:01 Yes, you can mix with certain pain medications, like morphine or clonidine or even ziconotide, which is derived from sea snails like the conchs. But there are considerations there. One, you have to be careful with the dosing. And again, just because somebody could put morphine in your pump doesn't mean you should put it in your pump. And the other thing to think about is, I don't know how true this is, but if you read the literature that the pump companies have put out, they say that different like opiate derivatives crystallize at the tip of the catheter. And so, there's been reports of catheters being obstructed by the pain medications themselves. I have ever only seen/heard of one patient where that has happened to, and they had only baclofen in their pump. But it's something I throw out there, so you will know.

**Dr. GG deFiebre:** 43:04 Okay. And then how often does the pump need to be replaced? I don't believe it lasts forever, so.

**Dr. Miguel Escalón:** 43:08 Yes, seven to ten years depending on the brand of your pump. So, it's really, I would say like six to eight, because we always had to do it about a year early. So, unfortunately, there's no way to kind of go in and just like do a little thing in the office and like open the lid and like put in a new battery. They have to replace the whole pump. They don't always replace the catheter. So, if you talk to the surgeon and you really want the catheter replaced, because you heard me say the catheter is the most common malfunction. And there's been no studies. It would be interesting to look back and see of all the malfunctions, are there people that had their pumps changed but not catheters?

So, you could ask for that. It makes the surgery a little bit more labor intensive because you need the two incisions again. But usually when they do go and they check the catheter for friability to make sure it's still nice and bendable, and if it's getting like a little bit hard or just looks funny, they'll change it. And they all will also access the catheter through the side port during the surgery to make sure it's like flushing and flowing. So, they'll like flush some saline and other stuff. So, they do check it, but again in the spirit of full disclosure.

**Dr. GG deFiebre:** 44:25 Okay, and then lastly, I have one question that I've been asked before that I didn't know the answer to. It's regarding how pregnancy might impact the pump. Have there been pregnant patients who have gotten a pump either during pregnancy or after or before?

**Dr. Miguel Escalón:** 44:40 Getting a pump during pregnancy would be pretty difficult, just because having general anesthesia during pregnancy is ill advised. The act of becoming pregnant while you have the pump is doable. The consideration really is the same of that of like a growing person is, would the change in your body habitus or size of your abdomen pull the catheter out basically from the spine? So, it's just something that has to be monitored. You can kind of measure it and things can be adjusted to a degree. So, if you wanted to become pregnant while you had a pump, probably what we would do is slowly decrease your dose and really talk to your OB and find out what medicines would be safe and try to manage your spasms as best we could on the lowest possible dose so that if the catheter, even if it doesn't come out, it could maybe be pulled down. And that could change the – think about we're talking about like the gravity, it could change how your spasms react. But it's possible, it just needs to be coordinated. Pregnancy itself can change your spasms.

And so, there's a lot to think about like, if you're in a wheelchair, you might need a different chair during that time, because you need a different cushion. If you're transferring on your own, you may not be able to anymore, because your arms may not be long enough to reach around your belly. And so, you might need to switch to a Hoyer lift. So, there's a lot of coordination that is involved in becoming pregnant. But it's doable. I'm not trying to scare anyone away from doing it. You should definitely do it if you want, but you definitely need to discuss it with your docs and get an OB that has some experience.

**Dr. GG deFiebre:** 46:30 Great, thank you. And so, I think we talked about a lot, is there anything we didn't talk about that you think is important to mention about the pump or the process or anything regarding that?

**Dr. Miguel Escalón:** 46:40 I'll just throw this out there. I've had people like go on vacation to other countries and then email me and say, "Hey, my pump's running out. I'm in India. What do I do?" And I have to try and find someone or at least help them track down the medicine and like talk somebody through it on the phone. So please, if you're going like away on vacation, anywhere around when your pump is due, because anything could happen, like there could be a flood and you can't leave. Let me know or your doctor know or look up doctors in the area that you could go to. Like, what if your pump malfunctions – like, you need to kind of have that backup plan and have an idea. So that's the only other thing I'd throw out there. You kind of have to – you can still go wherever you want, but you have to plan in those little ways, because it might take me a couple days to find someone in India.

**Dr. GG deFiebre:** 47:36 Yes, that's a good point. And then you mentioned that oral baclofen isn't used for withdrawal. Is there anything someone should have kind of on hand at home in case or if they travel and they're somewhere and they can't get to someone to do the withdrawal other than oral baclofen?

**Dr. Miguel Escalón:** 47:54 Yes, you can have oral Ativan or Xanax handy. The oral baclofen can help some, but it's not going to prevent you from going into withdrawal. And honestly, the oral Ativan and Xanax won't either, they're all a way of buying time, but the Ativan and Xanax will help more. So, you can have that handy, you can travel with it. I do have some patients that have it kind of like in the cupboard. But check it before you travel because it can expire. So, if you had it sitting up there for two years, because you never used it and you take it with you and it's expired, that's a problem.

**Dr. GG deFiebre:** 48:33 Right, got it. Well, thank you so much for taking the time. I really appreciate it.

**Dr. Miguel Escalón:** 48:37 Yes, sure thing.