

Nurse Linda- Neurosurgery January 2018

Julie: Hi, this is Julie Lubinski. I'm associate director of digital for the Christopher and Dana Reeve Foundation, and I'd like to welcome you all to this month's live chat with Nurse Linda. Let me tell you a little bit about Linda. She is a leader and a provider of rehabilitation nursing for over 40 years, most recently developing active based rehabilitation strategies.

She also writes in our online community and as Nurse Linda, she moderates that and takes your questions there and once a month, we are lucky to have her live to answer your questions here, and I'm going to turn over to Linda because we have a special guest today.

Hey Linda.

Linda: Hello. Thank You Julie and hello everyone. Just a reminder before we start the webinar today, I want to remind everyone that it is flu season as you probably all heard continuously through the news and other media sources. But remember, good hand-washing is the best defense against the flu. If you're unable to wash your own hands, be sure your caretaker is washing their hands. We are having a little dip in the flu right now which is lovely to see, but usually, it's not gone. It'll come back with a second wave. So it's not time to let down our guard but to be cautious of that.

As Julie mentioned, we do have a guest speaker today, which is very exciting. Dr. Justin Brown is our speaker, who is a neurosurgeon, who is at Harvard, and he is developing a new line of specialty for neurosurgeons to be working with individuals with spinal cord injury. So we'll be talking about some things today, some surgical procedures that are current, that are probable, and some that are out in the future. So this will be kind of an exciting day, and I am going to ask Julie. For some reason, my slides they're not advancing, and I think it's because I was hitting the wrong button.

So there's Dr. Brown, his contact information, and remember, this is recorded. So if you want to get in contact with him later, you'll have his information, if you need more information about what he does.

So welcome Dr. Brown.

Dr. Brown: Thank you very much.

Linda: It's nice to have you with us today. We're very happy in that you could take the time to do this. I thought we'd start today with just a little information about the nervous system, the difference between the central and the peripheral nervous systems, if you could just take a little moment to describe that for us.

Dr. Brown: I think that's a perfect place to start. So as Linda referred to here, the nervous system is broken down into two components. There's the central nervous system, which is the brain and the spinal cord itself so everything that's protected and bone.

And then there's the peripheral nervous system. Those are the nerves that exit from the brain and spinal cord. They exit through the bone and they go out and eventually connect to muscles and skin to allow us to move our limbs and perceive the world around us.

Linda: And so injury can happen in either nervous system or both at the same time, right?

Dr. Brown: Absolutely.

Linda: And so we hear a lot -- oh go ahead.

Dr. Brown: Yeah, and so those are good to distinguish because that is what leads us into distinguishing between upper and lower motor neuron injuries. So the peripheral nervous system is what we typically think about when we talk about a lower motor neuron injury. When we injure the peripheral nervous system and have a paralyzing injury, it results in a flaccid or limp extremity.

Whereas, when you injure the central nervous system, having an upper motor neuron injury, we usually have tone rigidity and sometimes spasticity. And that's really important in our reconstructive procedures because they are very different injuries that need to be treated in different ways.

And I often find that that gets confusing in spinal cord injuries because once we get down to the lower thoracic and upper lumbar, we're usually dealing with a primarily lower motor neuron injury because those nerves actually live inside the spinal canal and travel a distance to it before they exit. So lower thoracic and upper lumbar injuries are primarily lower motor neuron injuries.

Linda: So that is a good topic to talk about for just a moment because as you said in the central nervous system, those nerves are encased in bones, the skull and the vertebrae, but as the spinal cord exits in the lower part of the spine, that bony component is not there making those nerves peripheral nerves, correct?

Dr. Brown: That's correct. Yeah.

Linda: Good. So that's a big distinction. I know we're going to talk more about that when we go. So tell us a little bit about the work you do, what you're interested in, and how you plan to develop this new specialty area.

Dr. Brown: Absolutely. So just standard neurosurgery for spinal cord injuries, what we do and what everyone is trained to do as a neurosurgeon is how to deal with these things as soon as the patient comes in after they've had a traumatic injury and has been injured in the spinal cord, the number one priority for us is to get the pressure off the spinal cord and stabilize the spine and hope that we can halt the damage or maybe even to some degree, reverse what's taken place. And that's what happens in the acute phase. We want to keep them healthy or keep the blood pressure up, get the pressure off the nerves, stabilize the spine and get the patients in a place where they can begin to recover and go on to rehab.

The next role we have is really in the sub-acute or chronic phase. So we're talking months and it can extend on to years out when somebody has properly been stabilized. They've had the acute surgery. They've had the rehabilitation and they've hit a plateau and they are

failing to make additional recovery. That's where we can step in and do procedures that will give them more function than what they finally arrived at.

Linda: Okay, so can you tell us what some of the surgeries are in the acute phase? And then you mentioned the stabilization. Are there any other surgeries that can be done to preserve or restore function in the acute phase? And what surgeries are available in the post-acute phase?

Dr. Brown: Okay. So in the acute phase, the standard care right now is approaching the spine either from the front or the back if it's the neck. Thoracic is typically approached from the back and then lumbar can be front or back once again. And the idea there is that after trauma, sometimes we have a bone that has moved in reference to another bone and is causing pressure onto the spinal cord. Sometimes we have a disc that has herniated or escaped into the spinal canal and is pressing against the cord. And the idea is that we need to go in and remove anything that's causing pressure on the spinal cord to make space for that spinal cord.

And then if they're no longer stable in reference to each other, we have to put screws in there and hold those bones in position so they can once again heal together and be stable and be safe so they won't later on move and cause pressure on nerves with the spinal cord.

So when we go from the front in the neck, it's called the anterior cervical discectomy and fusion and they can make a nice horizontal incision in the front of the neck and move right past the breathing pipe, the trachea and the esophagus and we can get right to the front of the spine there and from that angle, we can take discs out. We can even take bone out and we can put screws and fix the spine that way. And it's less painful.

But other times, you have to go from the back, and then we have to do an up and down incision and dissect the muscle away from the bone to get them and fix it that way.

Linda: So a lot of people will write in and say, "Why was my surgery done from the front of my neck when the injury was at the back of my neck?" So is that a good reasoning why because there's less tissue muscle to get to that injury, even though you're going from the front a longer distance?

Dr. Brown: It's actually not so much a longer distance. It's really that vertebrae and the spinal cord is really central, dead center in the middle of the neck, and so the distance is about the same. Usually, the choice is made based on what the primary component is pressing on the spinal cord. If it's disc herniating from the front, then we primarily want to go from the front. If it is, you know, bone fragments from the back, then we want to go from the back and sometimes it could go either direction and then things like ease of surgery and easier recovery and fewer segments fused or things will help us go one direction or the other.

Linda: Okay and then Dr. Brown, there's a question that is floating around all the time and actually people have this conception that when they have a spinal cord injury, because of the classification system, it will say complete injury. And so patients get the message that

their spinal cord has been completely severed. How often do you really see a completely severed cord?

Dr. Brown: Almost never. You know, there have been cases where that has taken place with a bullet right through the canal or something like that, but it is a very rare situation. Most injuries do damage tissue of the spinal cord, but almost always there is some connection from above to below. And in fact, a patient really cannot demonstrate spasticity in the muscles below unless there is some connection from above, sort of keeping the lights on.

Linda: So that's good news for a lot of people but different maybe from what they've heard. So when you're doing your work, you do immediate care. You get patients in a safe position stabilizing their neck, and then I know you do a lot of work further out from the injury. We have a question actually where somebody has written in, are their surgeries for people who are long-term, have chronic spinal cord injury, long term. But the question is, somebody who's been injured for 20 years, is that possible for people?

Dr. Brown: It is possible and the rule of thumb that I tell patients is, if you have some movement in that limb, there's a good chance we can give you additional movement. Now, each individual injury will determine how much additional movement, but usually, there's something more. And when we have cervical injuries or injuries of the neck, typically, folks can retain say shoulders and biceps and may have lost function below that. We can often give additional function to the hands or to the triceps if we at least have something in the limb to work with.

Linda: So how do you do that?

Dr. Brown: Okay, so the two primary methods to do that, one has been done for 30 years or so and that is called tendon transfers. And the other newer one that we've just been doing over the last seven to ten years is using nerve transfers. So in a tendon transfer, what we're doing is taking a muscle typically below the elbow that a patient has control of and we cut one end of it and move it into position where it's going to create a function that they had lost. So for example, when we flex our elbows, kind of bringing your hand towards your mouth, we know we have a biceps. There's a muscle underneath that called the brachialis, but in the forearm, there's another muscle that helps with that. It rises up when we flex our elbow called the brachioradialis, and because all three of them are flexing the elbow, you can imagine you can disconnect one end of the brachioradialis and you could put it to another function. The most common one is to move it into the thumb, so suddenly, we have the ability to pinch or flex the thumb against the other fingers. And so that's an example of a tendon transfer.

Now, a nerve transfer is the same concept, except now we're growing nerves to a new destination. And so you can imagine taking a nerve also to something that we have more than one up. There are two muscles that turn the shoulder out and there are three muscles that flex the elbow and there are three muscles that extend the wrist. We take a nerve or a branch of a nerve from one of those so we don't lose anything. And then we suture that to a nerve that goes to muscles that we've lost function of.

And so one of the ones we'll often do is the supinator. So that's a little muscle in the forearm. It's usually present on somebody with a c5 injury that will allow them to turn the hand from the palm down position to the palm up towards the feeling position. The biceps also does that so if they have a strong biceps, we can take it away and we'll never lose it and then we can send that nerve into one of the nerves that either extends or flexes the fingers. We have lots of good results from that connection.

Linda: And is there a therapy required when you do these surgeries? Do you have to have therapy before surgery and after? Or how does all that work?

Dr. Brown: Sure. So therapy is usually not critical before surgery. It is nice to make sure that the muscle that you would be moving or the nerve that you would be moving, they have very good control of, and we also need to make sure that the place we're moving it to that joint is okay. It's supple. It moves appropriately.

Some folks as you know, over time, if they're not getting proper therapy, they will develop contractures or their tendons will tighten down and you won't be able to move their fingers or wrist through the normal range of motion. We do need to get that freed up if that has taken place, but if it's free, there's not a lot of therapy beforehand. If it's a tendon transfer, there is therapy pretty quickly thereafter. We need to get it moving. We need to make sure that it doesn't get stuck and that is when you move a tendon and suture it to a new place, the tissues around it can scar up. We want to keep it moving so that doesn't happen.

With a nerve transfer, it's a little bit like getting a muscle pregnant. It does nothing for about nine months sometimes, until it begins to slowly wake up and it'd begin those little baby movement and then it grows into a really full strong muscle, but it takes a lot of time.

So for those we have the therapists exercise the nerve or the muscle that we took the nerve from, and then eventually, we'll see a twitch in the muscle we sent it to and then we'll use therapy techniques to combine the two movements and to strengthen the new movement until they really have learned how to make that move properly.

Linda: So when you're doing these nerve surgeries in the upper extremity in the arm and for the hand, this is really in the peripheral nervous system, correct?

Dr. Brown: That is correct.

Linda: Okay, and then what do you do for lowers? Do you have surgeries that in the peripheral nervous system to help regain function in the lower extremities?

Dr. Brown: We do. Now, when it's a complete thoracic injury, so right in the middle where you have no movement whatsoever in the legs, there's not a whole lot of really great nerve transfer or tendon transfer options because again, you must have some movement in the limb. You need to get more movement. But if we have a little bit, so if we're extending at the knees or flexing at the hip, then we can move tendons there and get a little bit more movement. So there are procedures. They're not as common as the cervical injuries, but there are procedures that can be done to the lower extremities as well.

Linda; So let's take this out in thought here. What if you are a person who has some movement but not against gravity. So say you can get movement in the pool, or taking advantage of the buoyancy of the water, would that be enough movement for these lower extremity surgeries?

Dr. Brown: That's not enough for a nerve transfer. Now, there are other techniques that are coming down the line that we think will show promise for that, but for a nerve or a tendon transfer, we really want to move a muscle or a nerve from a muscle that has almost perfect or full strength in order to send it somewhere else. Now, some of the things that are showing promise in the more minor movements are things like epidural stimulation which has gotten a lot of attention recently.

That seemed to be able to turn up the volume in some cases on those weak movements and make them into more strong movements to give us some additional strength.

Linda: So tell us a little bit more about epidural stimulation. How does that work?

Dr. Brown: Yes, so that is a device that really was developed for pain, and it's only sold on the market for pain. People usually put it in the thoracic spine for folks that have nerve damage in the lumbar spine and radiating in the legs and it causes a tingling or a buzz that replaces that. But beginning in the '80s a group in Vienna began to notice that if you put this down right at the end of the spinal cord before it becomes the peripheral nervous system, right at that area, the spinal cord is almost like a tubular brain. It is smart enough to be able to move the legs in a coordinated fashion and so forth.

And they found if you put it right there and stimulated at certain frequencies, in some patients, they could modulate what was going on. So when I say modulate, you keep changing the output. Some patients who had spasms or a lot of spasticity in the legs that was problematic, if they turned it just to the right frequency, you could cause those legs to relax.

In other patients who didn't have much movement at all, there was another frequency they could dial it to that would cause the legs to extend and become more rigid. And then they found as they kept working on that that there were certain frequencies you could get to that would cause the legs to sort of cycle through walking movements. And so that caused a lot of interest in that area, and you've seen in the last couple of years, we've brought this over the United States and in places like Louisville. We found that if we apply this to patients who do have connections through the area of injury, there are some where we can really enhance the kind of movements they have and get them walking better or moving better at areas below the spinal cord injury that they were barely moving before.

Linda: So now would you determine that to be surgery actually in the central nervous system, or is it adjacent to?

Dr. Brown: It really is adjacent to and so it's a relatively safe operation because we're not manipulating the central nerve. We were not cutting into the spinal cord or implanting anything. It goes right next to the spinal cord and it talks to the spinal cord, but it does not involve actually cutting any of the tissue there.

Linda: And so that's really an exciting advancement is it or is it not?

Dr. Brown: It is. I think it is.

Linda: That's still under study. So it's not available to everybody yet, correct?

Dr. Brown: It is what we call an off-label use right now. So no company has taken this through the FDA or Food and Drug Administration to get it approved as a treatment that insurance will cover. So if somebody wanted this placed at this point in time, it would essentially have to be an out-of-pocket expense which can be very expensive for an operation like that.

Linda: So if all the studies and the efforts and the trials go favorably, could you give us any kind of estimate how long it would take to get to the general public?

Dr. Brown: I would imagine probably five to ten years from now.

Linda: So not that far out unless you're waiting for it, and then it's a long time when you're the one doing the waiting.

Dr. Brown: That's right.

Linda: Yeah, it's a different timetable depending on what's going on. Are there any other things on the horizon that you can see?

Dr. Brown: Well, there are all kinds of studies being done here and there. When I was in San Diego, they were doing trials of fetal stem cells and in the thoracic spinal cord, and it proved to be relatively safe. I'm not sure that we've seen a lot of effects from that yet.

Here in Boston, they're doing a particular medicine that you put over the site of injury when that initial decompression operation is done, right after the trauma, that they are hoping will give additional function in the arm and hands after the trauma. So we'll see what that shows, but those are just two examples of studies that are really going on all over the world right now, looking at different chemicals, looking at stem cells, looking at different sorts of interventions, both in the acute period and the chronic period that we hope you know, in the next decade, will give us a lot more options on the table.

Linda: Absolutely. So lots of things are happening. It seems like there's a lot more research in spinal cord injury right now. Do you agree?

Dr. Brown: I do agree. A lot of interest.

Linda: Absolutely. It's really, things are really happening out there, which is wonderful to see. So I did see we had a few people with their hands raised and their hands are no longer raised. So if you guys wanted to dial back in and ask your question, we'd be happy to take those questions. There's some more information coming out. Oh, here we have somebody with their hand raised now. Let's see if we can click on to them. Okay.

Julie: We'll have to see if we have any audio questions.

Linda: Okay.

Operator: So if you would like to ask a question over the telephone you may submit by pressing star 1 on your telephone keypad. If you are using a speakerphone, please make sure your mute function is turned off to allow your signal to reach our equipment. A voice prompt on your phone line will indicate when your line is open. Again, that is star 1 if you would like to ask any question.

Linda: Okay, we have one that is now in the chat and the question is, what about if you can use and walk but not being able to lift your legs up. So what if somebody can use their legs and they can walk, but they just can't lift their legs up. Is there something that you could neurosurgically. that you could do to help that person?

Dr. Brown: I'm having trouble understanding exactly. So if they can walk, what can't they lift up?

Linda: That they don't seem to be able to really lift their legs up in the air. So they lift their legs enough to walk along but not really raise their legs.

Dr. Brown: But not really raise their legs. So then the question comes to down – (cross talk)

Linda: It sounds like there's some weakness maybe.

Dr. Brown: It could be weakness and also it could be rigidity or spasticity. And that's where that question when began with – the beginning of the talk comes in. So if it's simply weakness without anything resisting it, that's a little trickier, but if it has a muscle that's working against it because of spasticity, then we can go figure out what muscle is resisting the movement and go address that one directly.

So we at our Center are using EMG which is a way to test the muscles and see what each muscle is doing to contribute to the movement or to resist the movement. And as we put the needle and then test each of these movements when a patient is, for example, trying to bring their foot up or push their foot down, we can find out which muscles are helping, which muscles are hurting that movement and the ones that are hurting that movement, we can give a trial of Botox. I think a lot of people have heard of Botox. It's a medicine that you inject and it causes temporary paralysis of muscles.

And so if we do that Botox into the muscles that's resisting the movement, we can often allow that arm, leg, or hands to move much better than it did before.

Now, at our Center if that's proven effective, we go on and do a procedure called a neurotomy. And so that's essentially the surgical version of Botox. It's a little bit more selective, precise, and gives a lasting result. So if Botox was helpful, we don't want to do a neurotomy and that will last them forever and it'll maintain that ability to move.

Linda: So if the patient, if they find results with the Botox, do they necessarily need to have neurosurgery or is that a choice or a recommendation?

Dr. Brown: It depends on the case. It's always a choice because these are function-enhancing procedures. They're never required but they do enhance your quality of life. Botox often loses effect over time and sometimes is not effective in larger muscles. So those are two reasons why we would really recommend that they go on to surgery. If they

gain a really powerful and effective result with Botox, it is continuing chronically, then they should continue the Botox.

The procedure has been very useful for example when the patients who can walk have so much spasticity and those muscles will push the foot down, turn the foot in and curl the toes, and Botox just isn't enough to fully relax it and get their foot flat on the floor. But we can show that that's the direction they want to go with the Botox and then when we clip those nerves, usually that gives a lasting and effective result to get the foot flat on the floor and let them walk faster, make the leg on the whole feel much lighter.

Linda: Oh, so that sounds very beneficial, but lots to think about for individuals who are considering some of these options. So here's a question. For someone who's leaving the hospital for the first time in a wheelchair, what's your biggest piece of advice?

Dr. Brown: Maintain hope. I think that our medical system has spent a lot of time in the last decade telling patients, "This is your life from now on. And I want you to get used to it and don't get your hopes up" and I think that is really a detrimental philosophy and everybody's afraid of giving folks false hope, but one of the things I saw when we began down this pathway of doing surgery to restore function is, patients would get additional function that I didn't do an operation to improve. And the reason was surgery gave them additional hope and so muscles that they had never tried to move or didn't give full effort, they now were giving full effort and would discover things that they could have achieved all by themselves without my surgery, simply because they were now hopeful. They were checking their body out. They were trying every day to see what would change. Hope is really critical.

Linda: And I certainly have to agree with that because I see so often, patients that have gone to different rehab centers, and you know, I'll see them in their chair and their arms are strapped down. Their legs are strapped down. Every part of their -- sometimes their heads are strapped to the headrest which may be important to help maintain the head to be able to hold it up, but then that also doesn't allow for people to try to visualize and to think about moving their body parts and your body is always trying to heal itself, no matter what happens to you, your body wants to heal itself. So it's important to try every day as Dr. Brown says, to see if you can. You know, think about, I might move my thumb, move my finger, you know. Keep going through every body part as kind of a little exercise that you would want to do for yourself. That it can be very helpful when you see something starting to move. You can certainly get some therapy and start using that.

I have another question here that somebody's written in and we'll kind of adapt this question for a neurosurgery event. But we have a person who's written in that they're paraplegic and had a laminectomy on October 5th of last year. Since then, they've been suffering with a lot of neuropathic pain in the hip area which is excruciatingly painful. Any thoughts? He's taking some Percocet one to three times a day, but he's interested in possibility of nerve repair. So do you have any thoughts on people with pain and as you know, can you talk about, we certainly know there are medications that treat pain. We certainly know that it's difficult to find the right medication and the right dosage and to hit that happy place. But is there any surgeries that you would like to discuss for pain after spinal cord injury?

Dr. Brown: Yes. So I think one important thing for neurosurgeons, or the spine surgeons across the country to realize is, just because something occurs below the level of the spinal cord injury doesn't mean it can't cause pain. We often think of a patient who's had a bad spinal cord injury as, the only thing that really matter are the area of injury and things above that, you know, further up the spinal cord in the brain are the things.

But everything below the injury really shouldn't be contributing to their pain, and that really is not often the case. So when somebody has a horrible trauma that has resulted in the thoracic spinal cord injury, they may have also injured their lumbar spine, and they can have pinched nerves down below or injuries to their hip or other things that may get overlooked because people consider that a lower priority, or maybe not a concern, simply because it's below the level of injury. And I would just encourage them to go ahead and work that up. Get the MRI of the lumbar spine. Get the imaging of the hip and find out what's going on down there, and make sure there's not a problem that can be addressed to fix that pain.

Linda: So we see that so often where people have a spinal cord injury at one level and then sometimes there's not a scan done of the rest of the spinal cord, because everybody assumes, well, this is the level of the injury and sometimes there are other injuries at the time of the accident, or through disease process that brings on spinal cord injury that sometimes there are other things that are going on, but people just don't look because they think well, this is the level of injury.

Dr. Brown: That's right.

Linda: So there's a hand raised with Connie and Julie, I'm hoping that you can help me with answering Connie's hand being raised there, because I don't seem to be able to get her. I don't seem to be able to click into her question.

Julie: Yeah, is there anybody on the phone for audio questions?

Operator: Yes, ma'am we do, and Connie your line is open, please go ahead.

Linda: Hello, you're on the air.

Operator: If you're on a speakerphone please pick up your handset or depress your mute function. Your line is open.

Okay, it did no response. We'll move on to our next caller.

Okay.

Your line is open.

Linda: Hello, this is Nurse Linda.

Caller: Hello. Hi, can you hear me?

Linda: Yes.

Caller: Okay I was the person that asked the question about the neuropathic pain. Also, I don't feel when I have to have a bowel movement or when I have to urinate, and they told

me those nerves will eventually come back. Do you know if that's indeed the case, that that will happen?

Linda: Well –

Dr. Brown: What nerves are we referring to?

(cross talk)

Linda: Bowel and bladder function.

Caller: Yeah, the nerves that control bladder function and control whether or not I can feel to have a bowel movement. I'm told that those nerves may come back with further healing. Do you have any idea if that is the case?

Dr. Brown: There are certainly patients who have made late recoveries of bowel and bladder. I think it's always worthwhile to keep looking and checking and hoping for the best, but it really is kind of an individual level. We'd have to know more about your particular injury to be able to give you a good guess on whether you can expect that recovery. But I have seen many patients down the line recover some bowel and bladder function, yes.

Caller: Okay, thank you.

Linda: Yeah, it'd be a good idea to check with your personal physician and see if they have any testing they want to do or that they can give you a better prognosis for if that will return function for you.

Caller: And do you know if neuropathic pain ever goes away?

Dr. Brown: Well. It's really different for everyone. The source of the pain, whether there'll be other things contributing to the pain. How far out from your injury are you now?

Caller: I had my surgery October 5th. It was because of an embolism of blood in my lower body that was pressing against the spine and the pressure had to be relieved.

Dr. Brown: Okay. So within the first year, we expect that people often will make a lot of recovery in that pain over the first year. If the pain that lasts a year and a half to two years and has not changed in intensity that we'd become a little bit more pessimistic about it going away fully with time.

Caller: Okay, thank you very much.

Dr. Brown: You're welcome.

Julie: Operator can you do the next call?

Operator: Of course. Caller your line is open.

Hello.

Caller: Hello.

Linda: Hi. Is this Amelia?

Caller: No, this is Dennis.

Linda: Oh Dennis. Hi, do you have a question?

Caller: Yes, I do. About 12 years ago, I had a spinal cord injury. I fell out of a tree and I had to have a cervical discectomy and fusion of my c3 and c4 with grafting in place. And I'm just -- I can walk with the walker after a lot of therapy. I can walk with the walker but picking up my right, it affected my right side more than my left, and picking up my foot is really difficult. When I start to pick it up, it feels like it weighs 100 pounds. I'm just wondering is there any chance of getting into some research or is it anything available that could be done to help me better myself?

Dr. Brown: So what you're describing is a spastic injury. It's upper motor neuron because the lesion is at the side of 3-4 and so everything in your legs is going to be upper motor neuron related weakness. And so with that is going to be, as we described before, some muscles that really want to do the right thing and other muscles that are resisting that. So neurotically and Botox procedures we referred to are usually beneficial in your case and as epidural stimulation makes progress, I think that will show some promise in your case as well.

Caller: Okay, how would I get in contact with your Center to do that?

Dr. Brown: I think Nurse Linda there was an initial page that had our office number on it and so forth?

Linda: Correct. I'll put that back up again. So there there's the contact information so you can call that number and get ahold of Dr. Brown. There are also other neurosurgeons around the country who do the same or similar type of work of Dr. Brown. He's obviously an expert and we have him on the show today because of his abilities. But if you are encumbered by your payer to only go to certain centers, you can check also with your payer to see if there's a neurosurgeon who does these types of procedures in your health care policy. So if you're thinking and you know, because I know a lot of people have Medicaid in their State. They're limited to having procedures done within their State. If you have a neurosurgeon who's interested in some of these things, they can always contact Dr. Brown also and discuss with him cases. Is that correct, Dr. Brown?

Dr. Brown: That's correct.

Caller: Can you give me the phone number over the phone? I don't have that up on my computer.

Linda: Oh, the phone number is on the slide there. It's 617-643-5687.

Caller: Okay and I'm retired military so there wouldn't be -- I'm on TRICARE and Medicare right now. So I could just call and talk to them about that?

Linda: You could get --

Dr. Brown: Yes, that's correct.

Linda: You could get, you could set up a consultation with them.

Dr. Brown: You can call me up at that.

Caller: Okay, all right. Thank you.

Linda: Yeah. Sure. There are some other questions about people that -- there's a lot of questions I see in the chat box about people who are interested in bowel and bladder function and in the past, there have been implants, devices that people have been using to help with bowel and bladder control. Do you have anything new to add to those kinds of surgeries, Dr. Brown?

Dr. Brown: I don't. I wish that we either had access to the prior system or could get our hands on the new ones, the Brindley VOCARE system was effective. I mean, we'd used it in the United States for a while. That company didn't do well, but they're still busy overseas and in throughout Europe. They're used in patients that seem to get a good effect with this system to be able to empty their bladders and sometimes move their bowels and so forth.

I'm understanding that there is a new system and development in Cleveland. It will come out in the next year or two that will also do that, but I don't know how accessible it will be and who it'll be marketed to, but things are available. They're just not really have been available in our clinics right now.

Linda: But we expect changes on the horizon with some of these new devices. Basically, for bowel and bladder, it's an implant type of system versus some kind of nerve reconnection, correct?

Dr. Brown: That's correct. Now, we are also working on a nerve reconnection, but it would be really specific to patients who have had a lower thoracic upper lumbar injury who have control of their abdominal muscles, and we really made a lot of progress in animals making that connection effective, and hopefully in the next few years, we'll be able to bring that to patients as well.

Linda: Now, here's a question back Dr. Brown and just through your vast amount of knowledge, I hope that you have a response for this one, but the question is, what is the latest information on restoration of the optic nerve?

Dr. Brown: I hadn't -- unfortunately, I'm not up to speed on that one. There was some research at UCSD who'd been doing some research into that and felt like they were making excellent progress but I have not heard the latest. I don't think anything's hitting the market this year, but we're excited that something will come along and if it works on the eye, we sure hope it will then work in the spinal cord thereafter.

Linda: Absolutely. The thought is if you learn how to make connections with one nerve, you can make connections with any of the nerves. So that is the thought that you know is kind of the guiding principle. If anybody you know, we've had people ask for clinical trials. There is a site online that you can log on to. It's a government site and it's actually called clinicaltrials.gov; so if you type into your browser 'clinicaltrials' all one word, and then '.gov', you'll be able to search on the website for any trial that's going on in the United States or anywhere actually in the world that have some kind of FDA or funding from the United States. So if anybody's getting funding for a study from the United States, but they can be

anywhere, because sometimes people are doing studies in other countries, but they apply for funding from the United States. So any of those would be listed on the site. So you can get studies that are enrolling, studies that are just recently closed. But you can find out what their findings were. So you can search on spinal cord injury. You can search on optic nerve and all these studies will come up.

The facility that Dr. Brown just referred to is the University of San Diego, and so there's some work that we now know that's going on there about the optic nerve. So good information.

So let's see. Oh, we have another hand raised. Operator, can you connect us with that call?

Operator: We do have a few callers in queue but just as a reminder, star 1, if you would like to say it over the telephone, and if you found your question has been answered, you may remove yourself by pressing 'star 2.' We'll will now move to our next caller.

Linda: Hello. this is nurse Linda.

Caller: Hello.

Linda: Hello, go right ahead.

Caller: All right, thank you. My name is Luis. The question I have my son had an injury, a spinal cord injury and they fused c4 c5. He has regained movement on his hands and his legs a little bit. And my question is, how long does it take or does it need more surgeries as far as the nerves to be able to move a little more or be able to walk?

Linda: So Dr. Brown, what do you think about that?

Dr. Brown: Okay, let me understand it again. Did your son have a spinal cord injury recently?

Caller: It was two years and three months ago.

Dr. Brown: Two years and three months ago. Okay and he currently has no movement below the level of injury?

Caller: Yes, he has movement on his hands and he's able to move his legs just a little bit, up and down like you see, if he's sitting on his wheelchair, he he's able to raise his legs up and down and move the foot side by side a little bit. Go ahead.

Dr. Brown: Okay. So once we get beyond two years, we really are dependent on how hard we work to get more function back. The things that just sort of magically wake up usually happen predominantly within the first year. They can happen up to the second year, but after we get there, it really is dependent upon working hard and getting the body to sort of wake up muscles that has a little bit of control over, to gain more strength.

Caller: Okay, so more therapy?

Dr. Brown: So it'd be good to get enrolled in a program where there's you know, health maintenance where they're really going to help exercise him, and have a therapist to work with them and move things that are difficult to move.

Caller: Okay. Well, I appreciate your help.

Dr. Brown: Thank you.

Linda: Okay. thank you. Is there another caller operator?

Operator: Yes, ma'am and caller your line is open.

Linda: Hello, this is Nurse Linda.

Caller: Hello. Hi, this is Judy.

Linda: Hi, Judy.

Caller: Hi. So I'm calling on behalf of my brother, 62-year-old male. He's at four years status, post osteomyelitis t11 t12, I believe. You've already answered the bladder question. It sounds like there still could be some hope down the line for he's self-capping right now. He's had a normal MRI recently checked again. Everything looks fine there. He's had normal EMG, nerve conduction studies. He's able to go to physical therapy. He's got lots of strength. Everything is good there, but he has this terrible, I guess, neuropathy or numbness and tingling. It's not even -- he can't even really come and say that it's painful, but he has difficulty with balance. You know, he still uses his wheelchair. He has to lay down, gets very fatigued. I'm wondering you know, what would be the next step for someone like that? Where it's just like you know, he just complains about this tingling like these spark-type feelings and when he does have muscle capacity, he's very strong, but he's not walking. I mean, he's not doing anything.

Dr. Brown: And he's not doing anything because he has such a discomfort?

Caller: Yes.

Dr. Brown: Okay. Well, that is the problem with injuries to the spinal cord as it is. They sometimes can be more on the sensory side. They sometimes can be more on the motor side. That they're all mixed and they're all a little bit different. The fact that he had that abscess, he did injure the spinal cord and a lot of times those tingling, discomfort, feelings that are uncomfortable can persist, and they can persist a lifetime. They usually will become more tolerable with time, but they typically aren't just going to turn off one day. They will you know, get better.

So you really you know, want to get him you know, working with somebody who can help him with medications. It might reduce those feelings of paresthesia, some of the neuropathic pain medications can help.

Caller: I mean, he's on Baclofen, and he's on gabapentin.

Dr. Brown: Yeah, yeah. And those are -- the gabapentin is one of those and there's the Lyrica and the amitriptyline and the nortriptyline and those sorts of things. So you want to work through that, but some of it you know, and some of it actually can be addressed maybe with spinal cord stimulation, as well in the area above where he was injured. So that is worth having a conversation with his pain management doctor about. It's not the classic indication, but I think there is a role for it there. But you want him to be able to push through

the pain and really rehab, because if he hasn't much movement in the legs and he's got a lot of rehab potential, and we don't want the pain to stop him from trying.

Caller: But that's the thing. It's not pain, per se.

Dr. Brown: Right.

Caller: You know, it's that you know what it's like when people -- it's a discomfort, but it's not pain.

Dr. Brown: Right.

Caller: It's just that constant like it's constantly reminding you that there's a feeling –

Dr. Brown: Right

(cross talk)

Dr. Brown: It is interfering with his activity level, though. Is that right?

Caller: Exactly and that he feels like he almost can't really feel the ground beneath them in his feet. He doesn't feel comfortable and that he's going to fall like you know, and he did fall once at physical therapy and broke his hip, in between this time. I don't know how much of it is just that fear of not being stable even though he's got strong t's yeah so it's kind of –

Dr. Brown: Yeah, I would really encourage to work out as much as he can. Get in an environment where he feels safe, where he's got the support he needs, and really push it.

Caller: Okay, but maybe the neurostimulator might –

Dr. Brown: It might be working better, yeah.

Linda: So what I'm hearing you say is really work with the oral medications, the pills that you take by mouth. See if you can find the right combination there. But let's talk a little bit Dr. Brown, about that neurostimulator. Usually people have that one pain that's unbearable or if they can't tolerate the medications taken by mouth, or if they can't take enough medications by mouth to really control the pain. But you're indicating another indication where it's not really the pain, but it's just this constant irritation or this constant annoyance that you have with the stimulation. So are there any other indications for epidural stimulation that you can think of?

Dr. Brown: Well, I mean that is the FDA approved use is refractory neuropathic pain, and I know you're stating that this is not pain, but this is a sensation that is interfering with his ability to rehab really. And so you know that definition can become a little bit ambiguous and so it sounds like something that you would want to medicate, something you want to do anything you can to reduce it, to allow him to have better quality of life. And so in a way, it really is behaving like pain. And so I think that the modulation which is what this does may change what he experiences and in doing so, maybe would make it more tolerable.

Caller: Okay.

Linda: Any other recommendations besides, in your experience, besides the gabapentin and the Baclofen. I mean, you mentioned nortriptyline or amitriptyline or would it be worth him asking his doctor just to switch it out and try something different?

Dr. Brown: Or seeing a pain management specialist who really has expertise in those different medications to walk through it and know the new ones on the market. But the other piece is you want him to not be avoiding activity because of these symptoms. So if it's feeling unsteady at his feet, we need to get him in a place that's equipped so he has you know, a harness or parallel bars or something that's going to make him feel more comfortable so he can still work at rehabbing himself.

Linda: Okay, very good. Thank you.

Linda: Thank you and thank you for that call because there are certainly a lot of issues that surround pain and that's very difficult for people to deal with. And it's very challenging to try to get that pain under control.

Caller: And then it just leads to depression and then you've got the whole cycle going and then you know, so it's tough. Yeah.

Linda: Right. So thank you for calling in.

Caller: Thank you, too.

Linda: Sure. If you need any more assistance, or if you need to find help you can always call the Christopher and Dana Reeve Paralysis Foundation that will help direct you to different facilities, different locations. There's a peer support group there. So that's kind of nice to get involved with as well, because there are people who are living all over the United States with spinal cord injury. So if you're new to spinal cord injury, or if you've had a spinal cord injury for a while, that's a great opportunity to get involved to help other people and finding people who can help you with pain in your community or finding resources, sometimes even finding a place where you can go get your hair cut, when you're using a wheelchair, and just all kinds of things, besides the camaraderie of having people who've been through the same type of things that you are going through.

So I do want to thank Dr. Brown for participating in our webinar today. It was wonderful having you here. I'm sure that there will be a lot of people -- there are a lot of people that called in, and I'm sure there will be more that will listen to the recording.

So we very much appreciate you being here today, Dr. Brown. And Dr. Brown's contact information is on the second slide if you missed that. I also wanted to ask you to please complete the survey at the end of this webinar today, so we can get information about you not you know, necessarily who you are, but just so we have an idea about our audience and what type of things you would be interested in.

And I would like to mention that on February 24th, I will be at the Abilities Expo. If you're able to come to that, I would be delighted to meet some of our readers and listeners at the Abilities Expo on February 24th. It's going to be in Los Angeles, California. There are several Expos around the country, but this one will be in Los Angeles, and it's on February 24th. So

Dr. Brown, thank you very, very much for calling in with us and being with us today. We really appreciate your expertise.

Dr. Brown: Thanks so much for having me. I've enjoyed it practically.

Linda: All right and we'll talk again soon and thanks everyone for listening. Thanks so much. Bye.

Operator: And once again that does conclude today's conference. We thank you all for your participation. You may now disconnect.