Pediatric Rehabilitation Strategies and Surgical Interventions

You can view this presentation at: youtu.be/LqN8Tmta7fM

[00:00:00] **Roberta Pesce:** Welcome! Welcome, everyone, to another talk from Track Three, our pediatric talk. One of the major concerns for children following a rare neuroimmune diagnosis is recovery, and so during this presentation we asked Drs. Hutchinson, Rosenberg, and Dr. Bjorklund from Nationwide Children's Hospital to tell you a little bit more about pediatric rehabilitation and potential surgical interventions. They did have to run off, so unfortunately, they won't be able to stick around for the Q and A after this. But I do encourage you to still submit Q and A questions. Perhaps they can come back at some other point during the conference and respond via chat. So please, I would just say, even though we won't be doing the Q and A for this session, just to still send the questions that you may have through the Q and A section on the right-hand side. And also, just wanted to remind you all that we have closed captions available also on the right-hand side. All right. Over to you, Dr. Hutchinson, to start us off.

[00:01:08] **Dr. Melissa Hutchinson:** Hello! Good afternoon, and welcome to the session on pediatric rehabilitation strategies and surgical interventions. My name is Melissa Hutchinson, and I'm a pediatric neurologist at Nationwide Children's Hospital in Columbus, Ohio. And I run the neuroimmunology program there. And so, I just wanted to take a minute to introduce our neuroimmunology program and the personnel that we work with in clinic, both in clinic and within the hospital setting. And so, myself and then Dr. Setty Magana are neurologists. Dr. Kyla Driest is a rheumatologist, Karah Harvey, Dr. Karah Harvey is a psychologist, Dr. Camille Wilson, a neuropsychologist, and Dr. Alana Leever, a psychologist. And then we have our excellent pharmacist, Jim Herbst.

[00:01:59] And we really take care of all children with neuroimmunologic diseases. Some of the diseases that we treat include autoimmune encephalitis and then of course the demyelinating CNS diseases including ADEM, optic neuritis, multiple sclerosis, neuromyelitis optica spectrum diseases and anti-MOG related diseases, in addition to neuroinfectious diseases such as acute flaccid myelitis. And we really take care of children on the entire continuum from initial presentation and diagnosis of their inflammatory disease to their inpatient treatment and rehabilitation program and to their outpatient care and rehabilitation program. And we do that along with our rehabilitation team. And so, I'd like to actually introduce Dr. Nathan Rosenberg now to take you through some of the pediatric rehabilitation strategies.

[00:02:59] **Dr. Nathan Rosenberg:** Well, hi. Thanks, Melissa. Good to be here. Let me see if I can advance these slides here. There we go, cool. So, I'm Nathan Rosenberg. Hi, everybody out there in Internet-land. I think the task we have right now is to tell us about, tell you about things we're really passionate about in a period of time that probably isn't enough for us to display our passion. But I think that when Melissa and Kim and I work together, I think a lot of what we're talking about, a lot of what we're communicating to each other is how can we help kids and adults do more? How can we help people do more? And that's the whole concept behind rehabilitation.

[00:03:39] I think our time is limited to give you the full grasp of it, and I think the best opportunity we have here is to say, "Here's where we are, now send us your questions. Reach out to us. Let us know what we can do to assist." But we're going to give you an introduction to our program. And then right after I'm finished, Kim's going to give you some really cool insight to technology for things that we can do to make, to again, function is key. And I'll talk about that in a second. So, who am I? I'm a pediatric rehabilitation physician. So, I care, excuse me. I'm board certified in care of both adults and children. And my clinical focus, so inpatient consultation care, so that's where I see a lot of Dr. Hutchinson, but also outpatient management of those with neuroimmune disorders. And then we also have an inpatient rehabilitation unit here, and that is a 12-bed unit.

[00:04:30] And we have the availability of ventilator care, which I think is really important because we have a lot of folks whose function can be really improved but they aren't yet necessarily breathing as well on their own. So, if we look nationally at inpatient rehabilitation units, some of them will do ventilator support, some won't. We as a department, many, many, many years ago decided that the right way to do that would be to focus on that. Put our efforts into it. My job is to focus on functions. So, people say, "What do you do for a living?" And it's like, "Oh, it's hard to say." But the whole thing is that I'm not here to necessarily eradicate disease. It's more so you're here, let's get this better. So, what we often say is share with us what you have, and we will build on that. So, we see what we see, let's make what we see bigger.

[00:05:15] So in terms of talking broad strokes, what do we do? Early, early after diagnosis, so if you're watching a recording of this video and you're still way early and you happen to catch up on this, you're still in the hospital, this is where that conversation of inpatient rehabilitation comes in. So, by US mandates, 3 hours of therapy per day 5 days a week. I think a lot of institutions will get that number a lot higher in terms of hours of therapy per week, but that's the minimum it would be is 3 hours a day 5 days a week. Looking at improving function, so physical therapy, occupational therapy, speech therapy. And again, bigger institutions, those more outcome-focused institutions are going to add a lot more to that day, including therapeutic recreation, music therapy, things that reestablish identity when identity is changed.

[00:06:04] So something that we also do, more on the outpatient side but also on the inpatient side, is comprehensive spinal cord care. So, if there is a spinal cord thing going on, we do it. We're specialists in spinal cord. So transverse myelitis, the NMO spectrum. But also, anything that you come to us with your spinal cord, we say, "Okay, this is what we do." There's a list of all the things we covered. There it is on PowerPoint. I don't need to read them all off to you because that's just the beginning of it. And really, it's this broad spectrum of what's changing your life? What's changing your function? And how do we get you to things that bring you joy? So, there's the medical side as listed there. And then there's the counseling side of, you're here right now here's what we expect in 2 years or 5 years. Here's what we expect in terms of your function. Here are some long-term goals we can key you in on that are rational, okay?

[00:06:55] And then the other conversation that I'm, hopefully every talk we ever have with spinal cords is that we talk about either current sexual function or future sexual function. A lot of that is age dependent. But to

think that that is a large part of humanity, and the medicine is still relatively undiscussed. And so, we hope to make sure in that the term sexual health is a very broad thing but one that we make sure that we discuss with folks regardless of age, because it's either we talk about your current situation or your future situation.

[00:07:25] Another thing we do is bracing. I threw a bunch of abbreviations out there, and those are a bunch of abbreviations for braces that start at the ankle and go up to the knees or the hips or the thorax and the trunk and picking the right one for the right time and getting creative with them. And so, we tend to like to geek out about braces and say, how can we use a brace to enhance you or your child's function? We also think about hand bracing and wrist bracing and forearm bracing. Again, for function but also for range of motion maintenances. For folks that are challenging with communication, sometimes getting the speech out is hard. We have devices for that communication.

[00:08:04] And then at least in our department, I think a lot of rehabilitation departments, we say seating is an art. So, sitting, if you're going to spend a lot of time sitting during the day and maybe your chair has wheels, that that should be an art that you're sitting in, and that experience should be as positive as possible. And so, we have gurus in our department that are, a lot of their time just focused on maximizing how well that works. So that's what I'm covering today. Hopefully we can answer your questions as we get a chance to interact with you folks more and figure out where you're coming from and what we can do for you. I'm going to pass the mic on to Kim.

[00:08:42] **Dr. Kim Bjorklund:** Thank you so much for the opportunity to speak with you all today. My name is Dr. Kim Bjorklund, and I'm a pediatric plastic and nerve surgeon at Nationwide Children's Hospital and incredibly excited to be part of the multidisciplinary team that's here today with Dr. Hutchinson and Dr. Rosenberg. And I just want to build on what my two colleagues have already talked about today with an amazing team that we have here to be able to not only provide children with rare diseases with inpatient hospital care and rehab as well as outpatient therapies and rehab. But my role here is to talk to you a little bit today about what we can do to restore function in children by using surgery.

[00:09:26] And so, a huge thank you to Dr. Amy Moore, who really is a pioneer of pediatric nerve surgery, particularly for children with acute flaccid myelitis. And as you'll hear a little bit more in our talk today, it's just really been incredible to be able to have her here and grow our program and what we can offer children from a surgical standpoint. So also, a huge thank you to all the patients and families who have allowed us to use their children's photos and videos today. So, to talk a little bit about surgery to restore function for children with rare nerve conditions, what are the main options that we use for them? These two are really nerve decompressions and nerve transfers. And in this talk, we'll go into a little bit more detail particularly about the nerve transfers.

[00:10:15] But just a little bit of an overview about what they both are. So, nerve decompressions, this is the idea that whenever you've got any sort of trauma in the body around a nerve that there's fixed points where nerves can have a lot of pain and swelling and scar tissue. And we see this happen in a lot of different conditions whether it's trauma, whether it's an illness like acute flaccid myelitis. And basically, what happens is that the nerves can't work as well. They don't transmit those signals to be able to have motor or movement function and also to be able to have feeling. So sometimes kids will talk about having numbness and tingling. And this can be because there's a lot of pressure on the nerve.

[00:10:55] And what we've found is that by surgically decompressing the nerve, or releasing scar tissue or tissue around it, we can actually help children regain more function and significantly improve their pain by

doing this. Also, we'll talk a little bit about nerve transfers. And this is the idea that we can move a nerve around. A nerve that has extra function, we can move that nerve to a nerve that's not working to be able to help a muscle that wasn't working to move again. So where do we use this? We have in the past gotten a lot of our history from nerve transfers from brachial plexus patients and trauma patients in the upper extremity. We've also been able to translate this to the lower extremity and use it in conditions like spinal cord injuries and acute flaccid myelitis.

[00:11:42] So what's the timing of it? When do we want to do surgery for a child that may have a rare nerve condition? Well, as Dr. Rosenberg and Dr. Hutchinson talked about earlier, there's certainly a lot of medical treatment that needs to happen, and a lot of times children get better on their own or get better with rehab and with strengthening. However, we do know that we have a limited time window. We know that after about a year, between the 1-year and 2-year mark, we know that if a muscle doesn't have a nerve attached to it or a working nerve giving it input, that that muscle will degenerate or die off. And we only really have until that time frame in order to regenerate that muscle.

[00:12:26] So any time a muscle is not working without the nerve input for whatever reason, we're in that situation where unfortunately we have to try to get it new nerve input before that time frame to allow the muscle to work again. So, depending on where we are in the body, we're really in a limited time window because nerves regrow at an inch a month. And so, we have to get that nerve to that muscle within the time frame before it starts to die off at around a year. So, this brings me to why do we use nerve transfers. And this is the idea that we take a healthy, working nerve.

[00:13:04] So for instance let's say you have a condition where you can't bend your elbow because the muscle to bend your elbow is not working anymore, but you can bend your wrist really well. Well, we can take a little branch of the nerve that bends your wrist, and we can transfer that branch of the nerve to the nerve that bends your elbow. Now that's going to regrow. And within a few months, hopefully you should start to see some elbow bending. Now, you don't lose any of your wrist bending because you've got lots of other little nerve branches that still bend your wrist. So really what we're talking about is expendable nerves or a nerve that can do double duty.

[00:13:39] And the really neat thing about this is that it moves that nerve really close to the muscle. So instead of having to wait a year or more because the nerve has to grow all the way down the arm, we can actually transfer those nerves right next to each other, and they only really have to grow maybe an inch or so. And that can actually get the nerve to the muscle right away and help us with that limited time window that we have. So, here's just an example of what the little incision looks like here in yellow, when we are doing a nerve transfer in the upper arm, so really small incisions. And then inside the body when we're transferring those little fascicles, and then you can just see here that for all different sorts of patients, it doesn't matter about the size of the muscle.

[00:14:25] You can see that these are examples of patients who didn't have normal elbow bending and now have good strength elbow bending. So where do we use some of these never transfers and nerve decompressions? Well, here we're talking a lot about acute flaccid myelitis today, so this is one of the conditions. And again, Dr. Amy Moore has really pioneered the experience with acute flaccid myelitis and has learned from these cohorts of children over time that really when we're thinking about surgery, it's really based on what is missing and what's available. So, every child has a different pattern. Every child has a different pattern of injury, and we have to look at, what are the options? What's working? And then what's not and move those nerves around to be able to best help the child.

[00:15:11] So we've learned that we can translate what we've done in the upper extremity to help children with nerve transfers in the lower extremity. And so, again, this is just basically what we've learned over time, and as our multidisciplinary team has shown, we certainly know that a lot of children recover function, and we don't want to jump into surgery right away. So, we are trying to figure out when the best time is, and we've essentially found that in order to basically combine when we are able to give your child the maximum time to recover but also not lose that window of when the nerve and muscle need to regenerate is about 6 to 9 months from the onset of injury.

[00:15:57] And again, we've looked at, I talked about one of the other surgeries we do is the decompressions or releasing pressure on the nerves. And we found that in the lower extremity, this has been really, really helpful to, for both function and pain. So, this is just demonstrating that child here on the right side who's got obviously significant weakness of the leg but does have toe movement up and down, and we can use that movement. We can take fascicles of the sciatic nerve, and we can transfer those to stabilize the hip or to help to extend the knee or help to flex the knee. Depending on what the child needs and what's available, we can use those nerves and be able to move them around. Here's just some of what the incisions look like in surgery. So small, little straight-line incisions. And then just some of the results.

[00:16:46] And so again, I think we all feel on this team that what we want to do is just help restore function. And to be able to get a child out of a wheelchair and walking with bracing and other modalities for ambulation is just really, really exciting. And so, these are just some of Dr. Moore's experience here, where just demonstrating this young man who's gone from being in a wheelchair to having, being able to walk with bracing and just hugely life changing to be able to see this after nerve transfer surgery.

[00:17:30] And so again, here are just more examples of after surgery undergoing nerve transfers, nerve decompressions, just being able to get significantly better function. And again, just any function that we can help restore is what we're all here to do. So, thank you so much for your time today. We're really excited as a team here at Nationwide Children's to be able to offer multidisciplinary care to children with rare diseases. And so, to be able to talk to you today about what we can do with surgery to help restore function for children with nerve conditions has really been an honor. Thank you so much, and we're happy to answer any questions.

[00:18:20] **Roberta Pesce:** Thank you, all, so much for this really helpful and important talk. We really appreciate it. As mentioned, we won't be taking Q and As for this particular session, but we do invite you to move to the next session from Track Three that will take place at 2:40, so it's almost time I believe, at 2:40 p.m. Eastern Time. If you head back to the sessions area, you will be able to see it. It is a talk about transitioning from pediatric to adult care. It's a conversation by Dr. Sadowsky from Kennedy Krieger Institute and Cody Unser from the Cody Unser First Step Foundation. See you there. Bye!