Jackie Diels: Neuromuscular Retraining for Facial Paralysis Transcript from NF Midwest Symposium and iNFo Fair – October 20, 2018

Our next speaker is Jackie Diels who is our expert on nonsurgical facial reanimation. We're very pleased she came all the way from Madison to speak to us on her specialty. Many of us with NF2 and our families are subject to the 7th nerve paralysis and this is a lady who treats and manages that issue. >> JACKIE DIELS: Good afternoon, everybody. I'm so happy to be here -- thank you, Sue, and thanks to Dianna and all of you for inviting me. I am an occupational therapist, and I have worked at the University of Wisconsin for about 32 years. I was about 10 when I started. (Laughter.) So, I'm going to be talking about, as Sue mentioned, nonsurgical facial nerve rehabilitation after facial paralysis. The program itself was established in 1983, at the University of Wisconsin by my mentors. I always like to mention them because they were incredible. Paul Bach-Y-Rita and Richard Balliet, and they were the first to put together a comprehensive therapy program for people with specific facial nerve issues. In the amount of time that I have been there, we have treated about 20,000 patient sessions. It is all that I have ever worked with. And while I am still very parttime on staff at the University of Wisconsin, I am primarily in private practice now in Madison. The kinds of patients that I work with are people who have Schwannomas and that would apply to the NF2 population, acoustic neuromas, that are sporadic in the population. Meningiomas, other kinds of skull-based tumors. Salivary gland cancer for example. We have seen guite a few patients who have undergone surgery for that. I see people who have facial paralysis from viral causes, such as Bell's palsy. Most people have heard about Bell's palsy. Or herpes zoster which is shingles that can occur inside the mouth and/or ear and affect facial nerve function. I have seen people who had trauma from an auto accident or motorcycle accident. Lyme disease which is very prevalent in our part of the country. People who have congenital paralysis which is a condition where they were born with facial paralysis. And then I also see people who have had surgical reanimation after facial paralysis, to improve their function.

At the bottom I wrote no CVA. CVA is a term for stroke. We do not see people who have had a stroke. A stroke impacts the brain. And the people that I work with have facial paralysis because the nerve was affected, not the brain. And it causes a different issue. We see different issues in those people. So, I want to introduce you to one of my patients. This is Susan. And you see the caption there, as Cicero said, "The face is the image of the soul". I think a lot of people look at facial paralysis as though this is a cosmetic issue. This is not a cosmetic issue. Although there are cosmetic implications, facial paralysis is a communicative disorder. Because 80% or more of our nonverbal communication is through facial expression. I can stand

here and make one tiny facial movement that you can easily see all the way in the back of the room- and now you know I'm concerned or worried about something. It is not

a big movement but communicates easily. These are not huge facial movements. Normal expression consists of tiny movements that we never think about until something goes wrong. So here is Susan. This picture was taken three months before she had surgery to remove a right acoustic neuroma, also called a vestibular schwannoma. In this picture she's out having drinks with her friends after work. And here she is -- five years after surgery when she first came for treatment. Cognitively she's the same. She is still working, but, wow, you get a real visceral response to this. This is the same person. You can see that there is no movement at all on the right side of her face. Her eyelids are sewn shut because her eye doesn't close; and it protects her eye from exposure to air and from drying out. There is no expression at all on that side of her face. She has trouble eating, drinking, speaking, and obviously, communicating. She's smiling here. We'll come back to Susan later on. I like to go through the anatomy, because we don't really know how our face works. Nobody thinks about it until something goes wrong. It is just there. It works. Nobody really knows how the system works. So I like to go through it in a way that makes sense of it. There are 3 parts to the system. The first part is the brain. The brain is like the generator in an electrical circuit. It sends the signal. The facial nerve is like the wire that connects the generator to the bulb. It transmits signals from the brain to the muscles. The bulb is like the facial muscles. You can have an injury anywhere along the system, so for example people who have strokes may have some damage to the brain/generator. The wire, the nerve, is okay. And the muscle, the bulb, is okay. I recently treated a child who had a dog bite and his facial muscles were injured. His brain and nerve were okay, but the muscles/bulb weren't working properly. For the people that I work with, it is a problem with the nerve itself, the wire that connects the generator to the bulb. If you unplug the wire from the wall, no matter how many times you turn the switch, the lamp bulb will not go on. So we're working with that part of the system. So here is the brain, the generator. What this diagram is showing is the part of the brain that generates movement. The little cartoons you see around the outside of the brain indicate how much "brain power" is devoted to movement of these certain body parts. Here you see a huge chunk of the brain is devoted to facial movement. And then you have kind of a big section devoted to the hand. Tiny little section devoted to the arm and the shoulder and the belly and the butt. And a tiny little section devoted to the rest of it compared to the face. And I believe the facial system receives the biggest portion because facial movement is so complex. There are many functional movements but also connections with the emotional part of the brain. There are connections for eating, drinking, speaking, as well as communication. This is a picture of the bottom of the brain. If I took my brain out of my head right now and flipped it upside down on the table, we could see that these are the nerves that come out of the bottom of the brain that go to

different areas and different functions of the body. -- I'm not going to do that today, by the way. Nerve number 1 here is for smell. Number 2 is vision. So forth and so on. And the one that we are concerned with today is nerve number 7 which is the facial nerve, and that's the green one that you see right here.

Nerve number 7 is right next door to nerve number 8. Nerve number 8 is the vestibulocochlear nerve. And that's the nerve on which a vestibular schwannoma grows. And you can see how close together they are. The tumor itself on a vestibular schwannoma can grow and press against the facial nerve, or just in the course of doing surgery to remove the tumor, the facial nerve can be manipulated and that can cause either a temporary or a permanent paralysis. There are other functions of the facial nerve as well. You see some branches that go to movement. The orange branches here go to tear production and for production of saliva. The green line goes to the taste buds. There is a little bit that goes to sensation behind the ear. So it is a very complicated nerve that does functions that we never think about until something happens to it. There are between 6000 and 7,000 individual nerve fibers in the facial nerve. They come out kind of as a trunk behind the ear. The size of a piece of vermicelli pasta and splits into 7,000 fibers that create somewhere between 2000 and 3,000 distinctly different expressions. So we talked a little bit about expression. It also goes to a little muscle in the ear that dampens sound - some people get very sensitive to loud noises, or they get a fluttering feeling in their ear. And then we talked before about tear production and the salivary glands and the taste buds. There are 23 muscles on each side of the face, plus the lip muscle! It is very complicated. Look at this diagram. You see on all of these muscles there is an arrow that points in a specific direction. The arrow points in the direction that the skin moves when that particular muscle flexes. I wrote down here move skin, because if you think about it, what other muscles can you think of in the body that just move skin? I cannot think of any. All of our muscles move bones around joints, but the face has no joints except for the jaw joint and that's not the nerve we're discussing. The facial muscles move skin. The arrows that point up move the skin up. The arrows that point down, move the skin down and so forth and so on. Let's go through them. This is my favorite part. Frontalis muscle. Eyebrows up. Now this is audience participation time. (Laughter.) All right? Follow the arrows. Follow the arrows. Corrugator muscle pulls. the eyebrows down and together. Each muscle has its own job. And one muscle cannot substitute for another. This is orbicularis oculi, this is the muscle that closes the eye. Soft and tight. This is my niece, by the way. And here is somebody whose eye doesn't close after facial paralysis. She doesn't know her eye is not closing. She thinks her eye is closed, but she doesn't see anything because the eyeball rolls up under the lid which is a protective mechanism which helps the eye from drying out too much. Most people do that when they sleep. It's difficult to do it on purpose. The levator muscles, are the orange ones. The arrows go up. These muscles wrinkle the nose like something smells bad. This is the zygomatic group and is the most

misunderstood of all of the movements. Because these are the smile muscles. And we think we smile with our mouth. But in reality, we smile with our cheeks. So even by covering my mouth, if you watch me can you tell if I'm smiling or not? No. How about now? Yes. You can tell because you see the "apples" of the cheeks flex up.

Because these muscles attach to skin and in particular these muscles attach to the corner of the mouth, when the cheek flexes, the corner of the mouth gets raised. The corner of the mouth goes along for the ride. And just telling someone to smile with their cheeks instead of with their mouth will change the way in which they produce the movement. Does it make sense? This is the smirk muscle. This is the orbicularis oris. This is a sphincter-type muscle. It presses the lips together, rolls them in over your teeth, puckers your lips like a kiss and protrudes your lips like a whistle. Depressor anguli oris. You can see the arrow points down. This is the sad muscle. This pulls the corners of the mouth down. Depressor labii inferioris, shows your lower teeth. Mentalis muscle pushes the chin up and helps turn your lower lip out. You guys are good! Buccinator muscle is a muscle inside the mucous lining of the mouth and it helps to move food back and forth between the 2 sides of your mouth when you eat. It is not an expression muscle per se, but it can be a problem with people who have facial paralysis in a couple different ways that I will get into shortly. Platysma muscle is one on the neck. We don't think of our neck being part of our face, but this is the muscle that does this (indicating). Tenses the skin of the neck. And it is a facial muscle, located just under the surface of the skin. And when it flexes here in the neck you can see that it pulls the corners of the mouth down. Now all the of this anatomy is going to come in handy in just a few minutes. So remember it all. (Laughter.) I will not be giving a test on the names. Facial muscles are different than other muscles in the body. They actually have physiological properties that are different than muscles that move the skeleton. They resist fatigue. They resist degeneration. And they atrophy much, much slower than other muscles of the body. They perform highly precise movements. Little tiny movements. And they are different than other muscles because they receive emotional signals from the emotional portions of the brain. So I can be happy or sad, and my bicep is going to always look like this. But happy in the face looks like this. And sad looks like this.

These are the kinds of people I treat in the clinic. People with flaccid paralysis which is what we think of when we think of facial paralysis. We think of kind of a droopy, hanging face. People who have weakness which is paralysis that is usually in the resolution stage. People who have a condition called synkinesis or mass action which is abnormal facial movement which is completely different than flaccid paralysis. And then people who have undergone surgical reanimation or reconstruction. Most of the people I see who start off with flaccid paralysis go through a recovery sequence that looks something like this. So here is Angie, this picture was taken 10 days after her acoustic neuroma. And her husband documented her

progress through photos. So here she's 10 days out. And you can see that the right side of her face is pretty flaccid. It is down. And here she is at 2 months. Her muscle tone looks a little bit better, but the corner of the mouth is still down. Here she is at 4 months. Looking pretty good. Right? You can see that her smile is back. But if you look carefully at her cheeks, you can see her right cheek is not as bulky as the left. You see that? And that her right eye is more open than the left eye which means that the muscle tone around the eye hasn't quite come back yet either.

But she's on her way. At 6 months things are looking pretty good. And then, at 14 months, I get a call from Angie and she says, "Jackie, I was getting better and better and better and now I'm getting worse again." And at 15 months she came into the clinic and she looked like this. So, what happened between 4 months and 15 months that makes her smile not as good? That makes her eye now more closed than the other eye instead of more open. That makes her cheek quite bulky but in a long sort of way. And can you see there are some cords kind of popping out on her neck? So, what has happened here? I will tell you. It depends on how you look at things. And in the face, this condition is not straightforward and clear cut. So, when you look at this, there are 2 ways to look at this picture. Right? You can see the men standing around or you can see columns. Now look at these pictures. When we look at these two pictures at first glance they look like they are the same thing. Right? In both pictures the corner of the mouth is down on the right side. Neither person is smiling. But when we look more closely, we can see that in the gentleman, there is no activity in the cheek at all. That eye is just drooping down. The forehead muscle is drooping down and covering his eye. This is flaccid paralysis. And in the lady, we see something guite different. We can see that she has guite a big cheek ball, medical terminology, and that her eye looks different, but that her eyebrow is up on that side. Here they are again. Let's take yet a closer look. Now if we look at the corner of the mouth, we can see that the corner of his mouth is just hanging down. But look at what we see here. Can you see all of this banding on the neck? I can have the best smile in the world and if I pull my neck muscle at the same time, watch what happens. It moves down. Now I'm doing two opposing movements simultaneously. And because the facial muscles only move skin, the skin is being pulled simultaneously in two opposite directions, like a piece of fabric pulled into two opposite directions is going to look like it cannot move. So, it is important to know how to analyze what we're looking at. Is it paralysis? Or is it a condition called synkinesis? Synkinesis results from improper healing of the facial nerve as it recovers. It starts to make abnormal connections where too many muscles get linked together and they contract at the same time. And that distorts the direction that the skin can move. Does it make sense? And here we see the same two people, and you can see her neck is really pulling and her eye is pulling and her brow and her whole face, if you look at it now, that whole face looks really, really tight. In retraining, we work with people more as recovery progresses than right away

when they are flaccid, because when they are flaccid, no matter how many times you flip the switch on the bulb, it is not going to light. So, we wait until there is a certain amount of recovery, so we can start working. We work with people who are very far after onset of facial paralysis and in those people, we can see that the new learning they get is the result of the retraining process and it is not just spontaneous recovery. We work on coordination, not strengthening. Precision versus just exercising. And we see people in the clinic intensively and then they practice the program daily. We do not ever use electrical stimulation in facial retraining. The research does not indicate that it is effective in any way. In animal models it has been shown that it can interfere

with the nerve healing. Electrical stimulation reinforces abnormal movement patterns because what happens to the face when electrical stimulation is placed on it is that all the muscles just contract at the same time. This is not an expression. So, it doesn't train function. And people that we've seen who have had electrical stimulation appear to have more synkinesis than people who haven't. Who are good candidates for retraining? It is not an easy program so people have to be motivated to do daily work. There has to be good level of cognition, so for example, there has to be a certain age or maturity level. Typically for girls it is age 8 and for boys age 10. Sorry, guys, just the truth. There has to be a nerve supply. If the facial nerve has been cut during surgery and there has been no repair (which doesn't happen much anymore) retraining will not be able to help that. If that is the case, and there has been a surgical repair or reanimation procedure, we can certainly work with that. We do an intake and evaluation and all of these different measurements, but the most important part is the education. Because as I said before, we don't really know how our face moves. We educate for functional patterns, not maximum effort movements. And functional patterns in the face are low amplitude, they are tiny, they are soft, they are precise and effortless. We're not teaching people to move as hard as they can, but rather to move as naturally as possible. We have people pay attention to what the face feels like internally as opposed to using a mirror. Because the mirror can show you what it looks like, but not how it functions to move that certain way. And there is a certain amount of engagement of time and consistency on a daily basis. We have to allow time for learning. Where are the muscles located? How do they act? Now you in this room know much more about how the face works now than pretty much anybody. Right? Now you know the anatomy. Where are they? How do they act on the skin? How do they coordinate to create expressions? What functions do they create? For people who have just one-sided paralysis-- how does the unaffected, (the good) side feel? What does that movement look like? And using that as a model for good movement. And how do the two sides compare? So, for flaccid paralysis, the first and foremost thing is eye care. Eye care is absolutely critical. Most of my patients are being followed by ophthalmology. And my advice to them is to go by their ophthalmologist's recommendations for their eye

care. Here is the gal who in one session learned to close her eyes better. There is a certain technique that we can use to teach this. Somebody has to be ready for it, so this kind of recovery, this response you would not see in a totally, totally flaccid face. So, this person's face was coming back. But you can see after instruction she was able to close better. We also teach gentle stroking of the face at the beginning, right after surgery, and that helps the brain realize that the face is still there. Because our brain is constantly getting sensation signals from our facial movement that the face is there and still moving. But after surgery if the face isn't moving, the brain isn't getting those signals. So, this research was done with rats in Germany and the researchers found that if they had technicians stroking the face of the rat after the rat's nerve had been severed and reattached, that that rat got better functional recovery than rats that didn't. And it certainly doesn't hurt anything to do it. And then what I tell people right away is to let it heal. If there is no movement, there is no exercise. Let it heal. Just like a broken bone in a cast needs to heal, you wouldn't put electrical stimulation on it and you wouldn't exercise it to heal it faster. You would give it the time that it takes.

There is a time in the body for healing. And I think it is important to say again that the lack of movement at the beginning is due to the lack of that electrical wire signal, not because the muscle is weak. For people once movement starts, we'll start seeing them 3 to 12 months after the onset, focusing on symmetry. Small movements. EMG (biofeedback) sometimes. And if the movement isn't back in a certain amount of time, and it depends what surgeon you are seeing, that can go anywhere from 8 months to 15, 16 months, then people can undergo surgical reanimation. Here is a case study of this gentleman that I showed before. This is two and a half months after his Bell's palsy. This is a couple months later. This is the picture you saw earlier. He came in at this point and said, it is not getting any better. But you can clearly see that this is better than the first set of pictures. But recovery is slow. And it is not something that our eyes pick up very readily. Here he is about 6 months later. Now I would love to stand here and say, this is what neuromuscular retraining does. But truly, this is spontaneous recovery. He had Bell's palsy, and typically in Bell's palsy you get recovery within 3 months. His took a little bit longer, but it did recover. But you can see he did develop a little bit of that synkinesis. Now you can see his eye is squeezing shut which looks very different than the first picture. You can see the difference. Right? I don't want to say I didn't have anything to do with this because I did. I did tell him he really had to take care of that eye. So, I followed him in clinic. But really, this is spontaneous recovery. The next phase is paresis. This is weakness, this is sort of a transition between the flaccid paralysis and synkinesis. I could tell that she had movement. This is her first evaluation with me. You can see that she has some movement, but it was almost like she wasn't able to "find the address" of her muscles. And after a couple of days, I was able to teach her just by going through the

anatomy and having her practice things on her good side and learn how the muscles moved, able to teach her how to activate these muscles. This was not a miraculous recovery. It was just that she didn't know how to access them anymore. I talked about synkinesis earlier. It is defined as the abnormal synchronization of movement where muscles other than those intended contract at the same time. And it results in distorted expression. By learning how to suppress the abnormal movements, we can decrease the distortion and improve coordinated movement. There are 2 separate issues with synkinesis. The first is the face gets very tight, it can be cramped. It can be sore. And whenever you have a cramp in any muscles you know that you cannot move them very easily, so we work on stretching them out. The second issue is that the abnormal movement distorts expression. And you can see on this lady, I've got the green lines indicating the muscles we're asking her to activate, which are her smile muscles, and on her left side it is working very well. And on the right side the red lines indicate muscles that are flexing at the same time that should not be flexing. So, all of these muscles got linked up with her smile muscles during the recovery process, and what we're working on is de-linking them to decrease the distortion and restore more normal expression. Here is a similar kind of picture.

The focus is on precision, not power. On delinking the synkinetic movement to decrease distortion. We're not strengthening muscles but rather strengthening the brain's ability to coordinate and to access them accurately. And here is Emily and you can see these pictures are a year apart. She was working on the program. She was a very good student. You can see that she's improved significantly but I will tell you that this program does not provide for a 100% recovery. Once there is a facial paralysis and synkinesis, there will be residuals. We can improve them, but we cannot eliminate them entirely. There are several different kinds of surgical reanimation procedures. There is one called regional muscle transfer that takes one of the chewing muscles and attaches it to the corner of the mouth in people who have lost their facial nerve after vestibular schwannoma for example. So, they take one of the chewing muscles, they surgically detach part of it, flip it over the cheekbone and attach it to the corner of the mouth. With this procedure, a person can achieve a smile only by biting their teeth together. So, when they bite, the corner of the mouth goes up. Here is an example of that. There is another procedure that takes a nerve out of the back of the leg and hooks it into the unaffected side facial nerve, tunnels it across under the nose-- this is all under the skin so there are no scars. The surgeon pulls it across to the other side and then takes a small muscle out of the inside of the thigh and plants it there and then hooks the nerve that was placed across from the good side into that tiny leg muscle. The result is that when the person smiles on the unaffected side, the signal gets transferred across the face into that leg muscle that was implanted there and that contracts, causing the person to be able to smile that way. And here is a gentleman who has Mobius syndrome. A bilateral (facial nerve) paralysis from birth. This is him smiling naturally. And this is him biting down after he had the surgical procedure where he had the had leg muscles implanted in both of his cheeks. And that is driven by the nerve that bites down. There are really so many things going on in the surgical world. They are very confusing to us. To us and to the patients. In order for him to smile, he's biting. The initial visit for retraining is 2 to 3 hours which includes evaluation and starting the program. And people return to the clinic about every four to eight weeks depending where they are and how far they live from the clinic. I want to say 4 to 8 weeks for the first six months and then we decrease how often they come. But in between clinic visits they practice every day at home. We estimate that it takes 18 months to 3 years for the entire program. Usually by year 3, I see them only once or twice in that year. The clinic visits decrease as the program progresses. We estimate that 90% of the treatment is completed by the person on their own at home. We sometimes use Botox for people who have a lot of difficulty controlling synkinesis. Botox decreases abnormal movements by temporarily weakening the improperly contracting muscles. It allows for better movement because it decreases some of the abnormal pulling that distorts expression. Here you can see this is about a month after his Botox injections. We videotape and photograph each patient on an ongoing basis and find that they improve 1 to 2 grades on one of our evaluation scales. And that is to say that people who come in, let's say at 40% function, may get to 70%. Something like that. As I said before, nobody gets to 100%.

Gains that are acquired through retraining are retained. That was demonstrated in a study by colleagues in Toronto. We are currently working on some prospective clinical studies at the University of Wisconsin. So, everybody wants to know what happened to Susan. Here is Susan. I think it is important to just say that neuromuscular retraining isn't for everyone and it cannot help everyone. But we have quite a network of medical professionals, facial, plastic reconstructive and ENT surgeons around the country and around the world. And Susan did not respond to neuromuscular retraining. We worked for 11 months and saw no change. So we referred her to someone who was able to do one of those reanimation surgeries where they pulled one of the jaw muscles down and they were able to get her eye open and in order to smile like this she is biting her teeth together. If you notice there is a little crease here, see that? This was from a newspaper article that her hometown did about her. She clipped it out and sent it to me so show me what her result was. Even if it is not something that we can directly help for people with facial retraining, we can almost always find another pathway to help people who have facial paralysis. In summary, this is very much a patient-centered program because the patient is doing most of the work. I'm the coach. It provides excellent continuity of care after surgery and facial paralysis. It is cost effective in that most of the therapy is done by the person on their own at home. It is not the kind of program where you come into therapy two, three times

a week. Not anything like that. And it provides specific training based on the unique characteristics of the facial, neuromuscular system. Thank you very much. (Applause.)

I know we're running just a little bit late. I would be available for questions. I have cards if anybody wants them.

>> AUDIENCE MEMBER: I think we have 7 minutes. It is always a good time for snacks.

>> AUDIENCE MEMBER: Our little boy had a -??? He has gotten better now. He was -- his one eye would be worse. Now it seems to be improving. >> JACKIE DIELS: That would indicate that his nerve probably wasn't cut. >> AUDIENCE MEMBER: He never had any surgery. We assumed from the growth of the tumor changing. >> JACKIE DIELS: Maybe the nerve accommodated to that. The body is amazing. >> AUDIENCE MEMBER: We couldn't tell when he was smiling. Smile nicer for the picture. I realized, it is not him -- he is smiling. That is his smile. His smile was changed. Now it seems his smile is getting better and more improved. His lip tumor he had (inaudible) the smile, too, that seems to have gone >> AUDIENCE MEMBER: Two questions, is there a time after a surgery that after which there is down. >> JACKIE DIELS: After what kind of surgery? -- I don't recommend any type of intervention? >> AUDIENCE MEMBER: VS. >> JACKIE DIELS: That's a really good question. If it has been a vestibular schwannoma and the face is flaccid with no movement like that real droopy, droopy thing, typically by the time that person gets to 13 months, 14 months, depending on the surgeon, if it is still flaccid, retraining probably won't be very effective for that, and that probably is a surgical candidate.

If, however, the person has gone on to develop synkinesis, there is no time limit to when we can work on that. Because in that case we're not trying to resurrect anything dead. We're just re-coordinating muscles that are alive but that are uncoordinated.

>> AUDIENCE MEMBER: One other question is, the nerve testing, is it the EEG? >> JACKIE DIELS: EMG. >> AUDIENCE MEMBER: Excuse me. Is that a one time, one shot never going to change test? If the test revealed not much nerve function or little nerve function but some -- I think it said -- muscle function fine. Which I guess isn't changing. Would a repeat of that be recommended? Or is that just pretty much the answer? >> JACKIE DIELS: In my practice I don't -- I really don't go by those readings very much. Because it depends -- it depends on exactly where those needles are put. I go by what I see. >> AUDIENCE MEMBER: What you see. That makes sense to me. >> JACKIE DIELS: If there is some function, then usually if we can capture that, we can harness it. >> AUDIENCE MEMBER: The test is -->> JACKIE DIELS: The test is not a be all or end all. >> AUDIENCE MEMBER: I have a question. It is kind of -- I'm an engineer so I understand the lamp. (Laughter.) I get the lamp plugged in. I guess I'm trying Provided by NF Midwest www.nfmidwest.org February 2019

to understand it sounds like you are consciously teaching things. When does it become subconscious that >> JACKIE DIELS: Yeah. Is it the brain or the cord being vanked they just do it? Am I making sense? and trying to get to the brain? I'm kind of lost to understand that. >> JACKIE DIELS: When the nerve gets damaged, some of the nerve, those 6 to 7,000 wires, like a fiberoptic cable, some of them will get damaged. But they regrow. When they regrow improperly and attach to the wrong muscle. That's when you get the synkinesis. It is kind of like learning how to play piano. First you learn where middle C is. Then you learn your fingering. Then you learn right hand and you learn left hand and you put the two hands together. Then you play chop sticks. Et cetera. Eventually as you practice, you learn it by heart. You don't need the music. >> AUDIENCE MEMBER: Translates from conscious to subconscious just naturally? >> JACKIE DIELS: Yes. We see that typically not until about the 3-year mark. It starts happening little by little. >> AUDIENCE MEMBER: Follow up to Dave's question. I have But it is a slow -- it is a slow process. had bilateral vestibular schwannomas surgically removed. I am deaf. Occasionally I do have very good facial nerve restoration. But -- and I don't have any problem closing my eyelids during the day. But at night, sometimes I will wake up and my eyes are really dry. I put drops in. Or I'll even -- I notice my pillow is wet from I have -- I think I am drooling. I don't have problems during the day. I'm 11 years now after my surgeries. It doesn't happen all the time. Evidently, I'm not -- I haven't been able to do it subconsciously because when I'm sleeping obviously -- I'm wondering if you know that lady you showed you helped get her -- close her eyelid, you probably don't know if she has that problem at night. >> JACKIE DIELS: No. But a lot of people do. A lot of people have problems with dryness. I recommend --

>> AUDIENCE MEMBER: Just tape it shut? >> JACKIE DIELS: Some people do tape it shut. For you, if you are waking up and your eye feels dry, why not just use lubrication in it before you go to bed every night just to be sure. Just keep that really well protected. As far as the drooling, just looking at you and watching you talk to me, I don't think the drooling in your case is probably due to any kind of facial weakness. But I will tell you my husband drools in his sleep. >> AUDIENCE MEMBER: Maybe it is age related.