NF Network is pleased to present an all new NF2 webinar. Tessa Hadlock, MD, Director, Facial Nerve Center, Massachusetts Eye and Ear Infirmary will present on Facial Reanimation Surgery and address the different types of facial reanimation surgery and their outcomes in NF2. This advanced surgical technique is the process of bringing a new nerve supply to a specific muscle on the face to regain normal activity. Dr. Hadlock will address the different types of facial reanimation surgery and their outcomes in NF2. Mara Wernick Robinson, PT, MS, NCS will present on facial massages and facial movement and motor retraining.

NF2 and Facial Reanimation

February 29, 2012

>> <u>Kim Bischoff</u>: Hello everyone, I'm Kim Bischoff and we would like to welcome you to our webinar series. Tonight we'll be discussing NF2 and facial reanimation.

>> Tessa Hadlock, MD, director of Facial Nerve Center, Massachusetts Eye and Ear Infirmary will present on facial reanimation surgery. This will bring new nerve supply to specific muscles on the face to regain normal activity. Dr. Hadlock will address the different types of reanimation surgery and their outcomes in NF2. The second part of our webinar tonight will be presented by Mara Wernick Robinson, who will talk about facial massage and facial movement and motor retraining.

>> Mara Robinson is also from the Facial Nerve Center, Massachusetts Eye and Ear Infirmary. We've have 72 people registered for this evening's webinar. These webinars have proven to be an excellent way to reach individuals across the country. I would also like to thank Marcia with Captions Unlimited for providing the captioning this evening, and the NF2 committee which is Sally Richards, Nichole Servos, Barbara Franklin, Linda and John Manth. Just a couple instructions here tonight with the captioning there's nothing you need to do it just shows up on your screen and after each presentation we'll have a very limited time for questions and answers. Questions can be asked in two different ways. To write a question to be read out loud click the question box located on the lower portion of the webinar control panel.

>>To verbally ask a question you need to have dialed into the conference call number provided, click on the green hand icon in the webinar control panel, to indicate that you have a question. Your name will be called and your phone will be activated.

>>To remove the webinar control panel from the view of your screen, click on the orange rectangular button with the arrow at the top left portion of the control panel. This may be necessary to have a complete view of the Powerpoint.

And now I would like to introduce to you Dr. Tessa Hadlock. Thank you, Dr. Hadlock.

>> <u>Dr. Hadlock</u>: It's an absolute pleasure to address this group and talk about what the sorts of interventions there are that we can perform for facial weakness and I'm going to try to run the

gambit of sort of all the different facial interventions, from the surgical standpoint and then we can segue into physical therapy in the second half with Mara Robinson. So here goes.

>>People have been interested in managing facial paralysis really for hundreds of years. The field of facial paralysis management really sort of began in the early 1800's with a very prominent neurologist by the name of Sir Charles Bell, who actually discovered that the facial nerve controls facial expressions. And since then people have come to appreciate very, very deeply the importance of the facial nerve, not only for functions such as protecting the eye and blinking and keeping the nose open and the nostrils open for breathing and smiling, and articulating, but also the critical role that it plays in nonverbal expression. And I think we in the Facial Nerve Center have a very deep understanding of how important it is to be able to communicate nonverbally and I think for the NF2 population this is exceedingly important as a mode of communication and I think one reason why this subject is so relevant for tonight.

>>So as everybody knows, really, the facial paralysis can appear so differently depending upon the face that is affected by it. So in the newborn period the facial paralysis examination really is quite different from even in infancy and young children all the way through young adults and into the very elderly. So you can see, for example, that in young-young children, ocular problems such as dry eye or excessive tearing are really not dominant problems, but in the elderly they really are the most significant problem. So really depending upon the age and the soft tissue factors the examination and the priorities can be quite different.

>>But let's talk about NF2, specifically, NF2 can affect the facial nerve in lots of different ways, but the most common thing that we see is a loss of facial nerve function, either acutely following surgical extrication or debulking of an acoustic neuroma, or Schwannoma as the more correct terminology would apply, or sort of an insidious loss of facial nerve function over weeks, months or even years, based upon sort of pressure effects from tumors in the cerebellar angle, some of the areas where the nerves come right out of the brain stem.

>>So what happens in a patient who experiences facial paralysis, like this particular patient, the brow position can become unbalanced, and so this person is affected with facial weakness on their left, and like many NF2 patients we actually see a paradoxical hyperelevation, like a little bit of a too-high position of the eyebrow on that side.

>>The other thing that we commonly see is incomplete eye closure even with full effort. We see that the nasal base is sort of rolled over toward the healthier side and in fact this can cause nasal obstruction on that side.

>>We see that that nasal labial fold, the normal crease between the nose and the mouth, is sort of effaced or softened in that area and of course we don't see the right movement at the corner of the mouth with smiling. We also don't see the lower lip able to curl down or out like puckering or saying the sound 'ooo', so lots of different functional and aesthetic issues.

>>Now, really to address the myriad complicated issues that we see in facial paralysis, the Facial Nerve Center was begun here at the Mass Eye and Ear Infirmary in 1989, so really we've been going over 20-years. And our group has really grown over the years to encompass plastic

surgeons, facial plastic and reconstructive surgeons, people from the otology side, ocular plastic specialists, physical therapists, and we do quite a bit of communicating with neurosurgeons and neurooncologists. Dr. Scott Plotkin, whose name I already heard today, amongst them. So really I think the problem is sufficiently complex that a single clinician wouldn't really be able to handle all of the issues but the right team might in fact be able to work in concert to provide the right kind of thorough care, if that makes sense.

>>So when we talk about care for patients with facial paralysis, particularly the NF2 population, really I would say the cornerstone of our management is what we would term multimodality management. And what we mean by that, it's not really the right kind of managed care you might be taking for your facial paralysis or NF2, whether it be Avastin based therapies or those kinds of things. It's not isolated to physical therapy, in terms of soft tissue techniques, stretching and neuromuscular retraining. And it's not isolated surgical therapy, like just the muscle transplant or just an eyelid weight. It's sort of a combination of these different modalities, put together, like the Venn diagram shows on the left-hand side.

>>So Mara and I and others have put a great deal of thought into this sort of concerted global effort, if you will, to take care of facial nerve patients. And we did write that up, and I'm sure it's something that the interested patient could actually identify just through Pubnet or other types of search engines, but this was published in about 2006. So I would refer the interested attendee to that manuscript.

>>So let's start of sort of thinking about how we assess patients with facial paralysis, and one of the biggest things that has been a challenge for clinicians is that it's very hard to look at patients in a standardized fashion. What we've tried to do is develop a little computer program and we call it the facial-gram. Up here I've termed it the 'smile analysis' but in fact we use this program to measure the distance between the upper and the lower eyelid. We use it to measure how collapsed the brow is in a particular individual and we even use it to measure sort of the nasal base collapse in patients with facial paralysis. We of course use it to measure smile and you can see here this NF2 patient preoperatively, before smile surgery, attempting to do a big smile and then here she is postoperatively trying to do that smile and you can see that we're able to quantify the vector of her smile. Both an X, a Y and sort of a Z vector, as well as the angle produced when she smiles and how much that changes pre- and postoperatively.

>>So having developed a quantitative system for looking at smiles has actually helped us communicate in the facial reanimation world with one another and figure out what the best techniques are.

>>It may sound silly to the lay person but really trying to have a good assay or a good measurement of what you're doing is the first step in trying to get better results over time.

>>So, you know, each patient that we see in the Facial Nerve Center obviously gets a history and a physical examination, they get a standard set of photographs, we take a video clip, we perform that quantitative analysis I just showed you and then we discuss in a group format amongst the clinicians offline how to manage that particular patient.

>>So all of that occurs and what I'd like to do now is sort of shift gears and talk about, well, what are some of the types of interventions that we might think about doing for patients with facial paralysis from a surgical standpoint.

>>Later you'll be hearing from Mara what happens from a physical therapy standpoint but the critical element is just to remember that these things work in tandem.

>>So I'm going to talk just starting really basically at the top and going down the face. I'll try to make it somewhat brief but when we talk about the upper face, we talk about the eyebrow and we talk about the upper lid and we talk about the lower lid. So we look at each of those three structures sort of in isolation. So you can see that really here, those structures are controlled by the frontalis muscle I show you here and sphincter muscle and the orbicular that causes blink right there. The most common thing we see in NF2 is brow ptosis, that is to say drooping of the eyebrow and this can actually be a very significant problem, it cuts down on peripheral vision, it causes skin cells to fall directly onto the unprotected cornea, it leads to a hygiene problem and so forth.

>>So this is really not merely an aesthetic issue, I mean it doesn't look good, but it's much more a functional issue and really ought to be addressed surgically. We pick the eyebrow up kind of according to this schematic, we lake a little ellipse incision here, we elevate the tissues and we put a little dissolving polymer device actually right in the bone, right in the calvarium there and we hike up that soft tissue to the correct spot. And you can see here's the preoperative view, here's the postoperative view and we're really able to get this tissue kind of out of this gentleman's way.

>>So that's the most common thing we do to elevate the eyelid. There are some other techniques for it that are equally simple, they can take as few as 15 minutes and we do all of this just in the office under local anesthesia as if it were-- you know, as if you were having a cavity drilled, essentially.

>>Another big thing that we focus on is trying to get the eye to close better. That's for the upper lid that won't come down to meet the lower lid. And we do that by making a little incision in the upper eyelid right in the natural crease of the upper eyelid, and we put this little thin profile platinum eyelid weight, you can see with three permanent sutures with inset and if you can appreciate this is a patient preoperatively who is trying to execute gentle eye closure. She's got a huge amount of what we call sclera show here 10 days later you can see she achieved beautiful eye closure and you can barely see the remnants of the dissolving sutures in that lid. But I think this eyelid weight technology has come an extremely long way. We don't use the thicker gold weights that can promote capsule formation. Platinum eyelid weights aren't perfect but they seem to be extremely well tolerated by patients than the gold.

>>The lower lid can sometimes be the dominant problem, if you can appreciate the lower lid malposition of this individual here, she is with eyes open and then here she is with eyes closed and you can see the upper lid doesn't do too bad of a job coming down but the lower lid is just massively inferiorly malpositioned. So again in the office a tiny procedure called the lateral tarsal strip procedure, we make a little incision in the corner and we sort of loosen things and put them in a much more proper position. And here you can see here she is postoperatively with her eyes opened and closed and you can see it really makes quite a bit of difference. The nice thing about doing these ocular interventions is they take very, very little time they don't require anesthesia and if you are on a medication like an Avastin type medication we do need to take people off those medications for surgical medications but not quite as long as when we're doing more major facial reconstructive surgery.

>>Next we'll talk about the middle face and when I talk about the middle face what I really mean is the nasal valve, sort of the sides of the nose and also the nasal labial fold, which means the crease between the nose and the mouth. Then I also talk about the position of the upper lip and of course the oral commissure, the corner of the mouth that moves with smiling.

>>Now the nasal valve when that collapses and rolls inward with the paralyzed face we solve that by taking a little piece of fascia, just like this little strip that we get actually from the outer thigh and we make a little tunnel between the patient's temple area and the nose area and we literally tunnel this piece of fascia between those two areas.

>>And then we secure the fascia to the nose and we pull laterally and we were able to really open up that airway dramatically.

>>So these are two examples. Here is the preoperative view of the nose from the bottom and postoperatively you can see that we've opened that way out and the same thing with this patient where he's got this rolled-in nose to begin with can't breathe through that side but then we permanently open it outward. This is almost like a magic trick for patients who suffer where they can't breathe on that side. So that's something to kind of keep in mind.

>>All right, let's talk about smile reanimation surgery. I want to say this is really the holy grail of the kind of work that I do. How can we bring back meaningful smile when patients have lost that ability.

>>There are lots of ways to do it. Free muscle transfer refers to taking the muscle from another part of the body and bringing it into the face to introduce movement. There are also regional muscle options like temporalis muscle transfer. So, I'll talk briefly about that as we get a little further into things. There's also a way you can use material like what I showed you back here, just a simple static sling of fascia lata to pull up corner of the mouth I'll show you one case of that as we go on.

>>There's been a lot of debate about what the best muscle is to use for facial reanimation. I tend to favor the gracilis muscle. I have seen other muscles used, for example the pectoralis minor, I don't quite like the way it looks as much and it hasn't been as reliable in most surgeries and the latissimus dorsi muscle is also used, that's a back muscle, but that's not as relevant to patients in the NF2 population because that would be more useful in people who also have big facial contour defects. For example, post-cancer removal and so forth where they have a big divot in the side of the face as well.

>>So let's talk about the gracilis muscle a minute. It's a little vestige muscle that fits on the inner thigh here. We take just a little cookie of it out, in fact this is an older schematic and the piece we take now is even thinner than that. Also the front surface of it is removed so it's only about half thickness.

>>It gets removed out of the leg, but the leg functions completely normally afterwards because this is not a muscle that we use in our activities of daily living or even in sports. And you can see it here on the back table and here is sort of it laid out where it's going to go in the face.

>>What kinds of results can we expect after transplanting this into the face? So here I'm just going to show you four examples. Three of them are NF2 cases and one is an isolated acoustic neuroma case. Literally we have hundreds of similar cases for different etiologies and I think over time we have really been able to establish that it's a pretty reliable technique to use. So here is the preoperative smile and the postoperative smile. We always make a worksheet for these cases and I'm just going to run the video so that you can see.

>>When he's asked to make a small smile, he can do that. When asked to make a bigger smile, he can do that. And even a bigger smile than that. So this individual is able to learn to control that without a great deal of work.

>>Another NF2 case preoperative smile, postoperative smile, and let's run the video so you can see this movement is quite natural and in fact, going from sort of this to this, I mean she really looks just about normal in the way that she can express herself moving that corner of the mouth.

>>Here's an isolated acoustic neuroma case but I think it's very good for illustrating what can be done. Here's the preoperative smile and here's the postoperative smile. Let's run the video. Can everybody see that nice movement here? And he can really learn to move it incredibly naturally, doesn't even need to close his teeth in order to get this smile to move.

>>I think this is a child with NF2, pre-op smile and post-op smile. The video isn't actually embedded in this one so I can't show you but again a beautiful, beautiful smile postoperatively. Here are some other examples, a pre-op smile and here she is postoperatively. Same thing here and another example of what we can get.

>>So I'm strongly, strongly biased towards using the gracilis muscle transfer, particularly in NF2 patients because they don't have any of the conditions that usually lead to failure of that operation.

>>However, temporalis muscle transposition is an option. That's when we just take a little strip of muscle, one of the chewing muscles off of the skull, and we flip it downward toward the corner of the mouth. You can see that it looks a little bit weird at the very beginning as it needs to be over-corrected in order to function properly later. Here's an example of the preoperative smile and postoperative smile. I think this might even be a video. I'm going to ask her to smile in just a minute. And you can see that she does, she keeps a nice movement but it's not quite as natural as what we get with the other. >>This is another example of pre-op smile and post-op smile with muscle transfer. I would choose this in the elderly as it takes about 90 minutes as opposed to four or five hours the other surgery. And this is an example of an individual whose comorbidities were massive and was not able to have a free flap, so he just has those kind of pieces of fascia lata like I showed you earlier, picking up the nose, the nasal fold and the oral commissure. That's sort of what we can do for smiling. The lower face is an area we often neglect, but we in the Facial Nerve Center feel it's almost of equal importance to the other facial zones. When we talk about the lower face I'm talking about the lower lip, the chin, and even this neck muscle, the platysma. We see this lower base asymmetry on the paralyzed side, the individual isn't able to pull that muscle away and show the dentition. We weaken the healthy side with a shot of botulin, and you can see a balanced smile. When a patient is like that, we can make it permanent like we have in this individual. She's got lower lip weakness on her right and with a tiny office procedure we can weaken the left side so she permanently has a better balance in that area.

>>Physical therapy I'm going to leave for Mara and really I would finish by saying there is a lot of room for improvement, but that we are doing a lot of sort of clinical research for patients and on patients as well as a lot of basic science studies that involve really trying to improve nerve regeneration in general with animal models.

>>But that I think that there is a great deal more hope for facial paralysis, particularly in NF2 patients, than what is sometimes commonly believed and that's where a facial nerve center, this Facial Nerve Center, can be an excellent resource. There are very, very few and reach out to your neural oncologist and try to make a connection. Our door here in Boston is always open.

>>And I hope that this information has been somewhat useful. I would be happy to take some questions.

>> <u>Kim Bischoff</u>: Dr. Hadlock that was amazing, very, very amazing and wonderful presentation. There are a couple of questions here that I'd like to read to you.

>> <u>Kim Bischoff</u>: One is do they have to grit their teeth to smile and the second is how soon after their surgery after facial paralysis would you recommend facial animation surgery?

>> **<u>Dr. Hadlock</u>**: The first question, at the very beginning, people clench their teeth to smile. But in about 95 percent of cases they don't they wind up not having to close their mouth to smile. They don't even have to bring the teeth together. It's learned and it's mastered and it becomes very second nature so it's not the kind of thing where you need to bite down.

>>That's not so much true of the temporal muscle, where they really do need to always bite down for that.

>>When someone has had VS surgery where the circumstances vary a lot. If the nerve has been sacrificed and we know that it's been sacrificed then I think as soon as the patient can stomach the concept of having surgery we ought to restore a smile.

>>If there is some probability that the facial nerve function is going to recover spontaneously, it's reasonable to wait even 12 months to see what the patient gets back spontaneously.

>>The problem is that neurosurgeons are eternal optimists about this and a facial nerve surgeon is an eternal pessimist about it, so it's hard to come up with the exact right answer.

>> <u>Kim Bischoff</u>: The next question is going to go to Barbara Franklin. I'm going to un-mute your phone. Barbara, can you go ahead and ask your question?

>><u>Barbara Franklin</u>: My question is how long does somebody have to be off of Avastin for one of the muscle transplants?

>> <u>**Dr. Hadlock**</u>: So it's a great question, Barbara and usually we work pretty closely with the neural oncologist who is the treating physician. I want to say I wouldn't be comfortable doing it unless somebody was off the Avastin for about eight weeks.

>> And I know that people are extremely sensitive about whether they're going to lose ground from a hearing standpoint though I will tell you that the patients where we've systematically taken away Avastin, gotten that surgery done and gotten that patient healed did not lose ground on hearing.

>> Now, I have, you know, only a handful of patients in whom I've faced that exact question, so I don't have, you know, 50 patients. And I bet you that if I did have 50 and somebody went off Avastin I would see some people losing ground hearing-wise. And in that case we would probably just abort the plan for surgery and go ahead and get them back on the drug.

>> <u>Kim Bischoff</u>: Thank you. And here's another question that someone has typed in. Could you please talk about periocular treatment, what it is and how it is performed?

>> <u>**Dr. Hadlock**</u>: Sure, that's the stuff that we talked about early the Periocular treatment really refers to correcting the position of the eyebrow to improve the peripheral vision and get the skin that overlies the cornea out of the way.

>>The eyelid weight would fall into that category of periocular reanimation and the lower lid correction would fall into that. There are also eyelid springs that only a couple of surgeons use in the United States, it's kind of an emerging technology as something that may benefit patients.

>>And there are also some reinnervation techniques that provide input to the oculi muscle, the blinking muscle but the problem in NF2 patients is that we rarely want to take input from the contralateral facial nerve because everybody has bilateral situations and no one knows when you might experience facial weakness on the opposite side.

>> <u>Kim Bischoff</u>: Thank you and here's one from Debra Miller.

>>><u>Debra Miller</u>:I'm amazed what you can do, my grandson had a mass-- I'm not sure I'm saying that right -- muscle transfer about two years ago and it can be tweaked, can you still do some of these procedures since he has already had one?

>> **Dr. Hadlock**: That's a great question and the answer is yes. When someone has sort of the technique that is available to them locally and it doesn't look great or it looks okay but doesn't have enough excursion, that's the kind of patient that would need-- that I would really need to study and look at carefully in order to decide what would be the best-- you know, the most appropriate course of action. But most often when there's kind of a suboptimal reconstruction we have something to offer that kind of puts the icing on the cake, if you will.

>> <u>Kim Bischoff</u>: Okay, and this one is going to go to Maria Sam, I'm going to un-mute your phone. Maria, can you hear us? Can you go ahead and list your question?

>><u>Maria Sam</u>: Sometimes people don't call into that number, and it won't work so type your question, Maria, maybe we can get to it.

>>Kim Bischoff: Let's see, if I can find another one here.

>>(Audience): What is capsulization from gold and does that cause them to not stay in or are platinum more likely to stay in?

>> **Dr. Hadlock**: So capsule formation from gold is basically a reaction of the tissues to the foreign body. Basically, it's a low-grade allergy to gold that about 9 percent of the population has and that capsule formation doesn't cause the eyelid weight to come out, it just makes it look like there's a bulky in the eyelid.

>>The other thing that can happen with an eyelid weight, either platinum or gold, is that it can extrude. That means that the body sort of rejects it and it spits it and it shows to the surface and needs to be removed.

>>Kim Bischoff: I'm sorry, what was the-- something about the-- hold on.

>> I don't have the question up here anymore.

>> <u>**Dr. Hadlock**</u>: Are platinum more likely to stay in? So, platinum weights in my experience are more likely not to extrude.

>> <u>Kim Bischoff</u>: Okay, I have Maria's question up here now.

>><u>Dr. Hadlock</u>: Okay.

>> <u>Kim Bischoff</u>: I have full facial paralysis, is the procedure the same?

>> <u>Dr. Hadlock</u>: For a full facial paralysis?

>> <u>Kim Bischoff</u>: Yes. That's correct.

>> Dr. Hadlock: Exactly, yes.

>> <u>Kim Bischoff</u>: It is the same, okay.

>> **<u>Dr. Hadlock</u>**: So yeah if somebody has a complete facial paralysis I would put in not only the muscle but open up the nasal airway the way I showed with that piece of fascia and probably also do some work around the eye, sort of lots of different things that would make the picture complete.

>> <u>Kim Bischoff</u>: And then there's another question and I think we could probably broaden this one, this one is asking if there's anybody in Iowa who does that a provider and I suppose you could probably address that nationally.

>> **<u>Dr. Hadlock</u>**: So there are some-- it's a tough question, there are people-- a lot of people claim to do the surgery, but there are few people who really are very well trained, in other words, they had enough experience during their training time to go out and be comfortable with it.

>> I did just train a fellow for two years and he is now in Iowa at the University of Iowa. His name is Dr. Douglas Henstrom and he's someone who I personally know has joined me on 80 of these cases and so that's a person I would have a lot of confidence in.

>>In general, you really need to very carefully assess whether a person truly has enough experience with it and I don't have the secret to eliciting a surgeon's experience. Everybody likes to sort of inflate how much experience they have with the problem and I just don't know exactly what to say about that.

>><u>Kim Bischoff</u>: They're asking how long does the patient have to stay in Boston for this procedure?

>> **Dr. Hadlock**: So normally what happens if someone comes to Boston is that we do the surgery on a Monday, I keep people in the hospital until Thursday, they'll stay in a hotel Thursday night and I'll check them in the office on Friday and if they look perfect they can go then. We do a lot of corresponding over the phone and I do have local facial plastic surgeons all over the country who will definitely take out sutures and things like that for me. But lots of people have found that it's not so much of a hassle to make the trip and that the time commitment isn't ridiculous.

>><u>Kim Bischoff</u>: Then there's another one right here. Scroll up a bit and I can see it here. It says what do you recommend for the small subcutaneous tumors that grow under the skin on the face? Surgery often results in a scar, what about rapamycin cream or are there other things which may help with those.

>> <u>Dr. Hadlock</u>: I don't know the answer to that, you know, I am so focused on facial paralysis that it sort of narrows me to a fault. I really only take care of the facial movement problems and

so I'm not as strong in the management of some of the other cutaneous conditions that we see with NF2.

>> <u>Kim Bischoff</u>: Okay, then there's another one here that looks like-- is a gracilis transfer more invasive?

>> **Dr. Hadlock**: More invasive -- well, there are two surgical sites because you've opened the face and the leg and the gracilis muscle transfer takes a bit longer because we're hooking up an artery, a vein and a nerve that we don't need to do in the temporalis transfer. But I think that the data show that the results with the gracilis transfer is so far superior in my hands and I think the hands of people internationally that I probably would not advocate the T-flap, the temporalis muscle flap, as a first-line intervention.

>> <u>Kim Bischoff</u>: Okay, let me see if I can get one more question, here. This one says I have had multiple facial surgeries attempting to fix the drooping, none was successful. I now have a Goretex graft, is what she's saying is in my face and is really fighting it. What can you do?

>> **<u>Dr. Hadlock</u>**: Yeah, I would not use a foreign material like Gore-tex in the face. I would probably-- you know, everyone's clinical situation varies so much, but I would probably kind of start over and think about something that could give some movement to the face.

>> <u>Kim Bischoff</u>: Well, there are no more questions here, Dr. Hadlock but we have Mara's presentation.

>> **<u>Dr. Hadlock</u>**: Yeah let's move-- yeah sure.

>> <u>Kim Bischoff</u>: Wonderful work, truly appreciate you giving us your time tonight. Thank you very much.

>> **<u>Dr. Hadlock</u>**: It's been an absolute pleasure. Okay Bye, now.

>> <u>Kim Bischoff</u>: We are going to take just a moment here and switch the screens over to mine so that Mara will be able to do her presentation.

>> Okay, can you see my screen?

>> <u>Mara Wernick Robinson</u>: Wonderful, perfect.

>> <u>Kim Bischoff</u>: And now we've got the captioning.

>> Mara Wernick Robinson: Do you want to move that over?

>> <u>Kim Bischoff</u>: Okay, go ahead Mara.

>> <u>Mara Wernick Robinson:</u> Okay, thank you for inviting me to talk to you this evening about facial rehabilitation. I'm going to use the word facial rehabilitation and physical therapy

interchangeably. I am a physical therapist, I've been working with Dr. Hadlock for 9-years now and I think you all have identified how amazing she is in just that short half hour. She provided you with some valuable information that I will now complement with how we handle patients before they undergo surgery, as well as after they consider going through the facial rehabilitation surgery and how physical therapy plays a role.

>> All rightee, you can hit the next slide, please.

>> **<u>Kim Bischoff</u>**: All right.

>> <u>Mara Wernick Robinson</u>: Great, as you can see from these typical faces, our face is the image of the soul and we have for so long taken-- you probably have taken for granted the facial expression that you have. When it is taken away from you, you realize how imperative facial expression actually is from showing happiness, anger, frustration and even some silly faces. Click on the next slide, please.

>>So from a physical therapy standpoint I'm going to speak to you about how we as physical therapists break down the examination of a face, from what we call impairments, functional limitations and disabilities. Secondly, I'm going to talk to you about the expectations and goals of facial rehabilitation. What physical therapy can provide for you and then I will spend some time going over specific components of facial rehabilitation. What to expect and what not to expect when you see a facial physical therapist. All rightee. Next slide.

>>When one suffers from facial paralysis, we break down the problem list into what we call impairments, functional limitations, and disability. Impairments are problems that occur at the organ level due to specific pathology. So when the problem is at the facial nerve, you suffer from facial paralysis, as well as sensory loss.

>>At the functional limitation level, you think about the loss of activities of daily living. So in facial paralysis you may have experienced problems with eating and drinking.

>>And from a disability standpoint, facial paralysis can significantly affect your role in society, with particular things like working with socialization.

>>So I'm going to be able to explain to you how physical therapy tries to manage impairments, what strategies we have at the impairment level, what rehab strategies we have to improve your function, as well as your disability. Next slide, please.

>> So at the impairment level, as I said and as Dr. Hadlock said earlier, one experiences motor loss of all the facial muscles, they can experience complete facial paralysis or partial facial paralysis, as a result of the neuroma surgery, as well as a sensory loss. In the chronic stage after a period of time, patients develop what we call muscle atrophy and hypotonicity. You can develop hypertonicity, which is muscle stiffness, and then one can often develop what we call synkinesis, which is aberrant nerve regeneration. If we have experienced surgical correction of the acoustic neuroma, sometimes that nerve grows back aberrantly, and one develops synkinesis. A pattern is when you smile, and at the same time when you smile your eye closes at the same time. So the nerve that's responsible for generating smile motion is now rerooting or aberrantly regenerating to the eye muscle as well. So I'm going to talk to you in a few minutes about how physical therapy can manage synkinesis.

>>And lastly, impairment associated with facial paralysis in the chronic stage is facial pain. And physical therapy is extremely helpful in managing facial discomfort, muscle stiffness, facial pain. Okay, next slide, please.

>>Dr. Hadlock mentioned quite a few of these functional limitations and spent the majority of her lecture of how surgery corrects limitations, how surgery can lift the corner of the mouth, lip motion and articulation. I will spend my time also briefly explaining how physical therapy can change these functional limitations. As I said, both before surgery, before you're considering surgery and then after you have considered any of her surgical suggestions. Okay. Thank you, next slide.

>>And as I had said earlier people with facial paralysis suffer from disabilities that limit their role in society. Things like going out and socializing, eating in a public restaurant, inability to return to work due to articulation difficulties, visual dysfunction, and pain. Oftentimes people are not comfortable with how they look as a result of facial paralysis, so they tend to isolate themselves.

>>I feel we at the Facial Nerve Center really play a team role in facilitating patients with facial paralysis returning into the community and feeling much more confident about how they look following our intervention.

>>I think once you walk into the Facial Nerve Center you'll look around, see hundreds of other patients that you feel you look like, you immediately connect to them and I think that our environment plays a role in making patients feel comfortable and returning comfortably to the world, so to speak. All rightee, let's move on to the next slide.

>>So when we see patients for physical therapy, we go through an evaluation, in conjunction with the time spent with Dr. Hadlock. We do try and coordinate the physical therapy visits on the same day you're evaluated by Dr. Hadlock.

>>We evaluate patients with a questionnaire called the FACE instrument. We evaluate people with an objective rating scale called the facial grading system or facial grading scale and we also measure your synkinesis as I described earlier.

>>The mainstay of the physical therapy treatment is five-fold. We focus on patients' education, helping you understand what role each of the muscles play in facial movement. We also emphasize how important relaxation is not only for the facial muscles but for the entire body.

>>Facial massage is a mainstay of the physical therapy program. As well as neuromuscular retraining that involves having patients-- having you look at yourself in a mirror and retraining the movement pattern.

>>We don't carry normal sensory feedback in our face like we do in the rest of our body, so we need to rely on visual feedback from a mirror. Then it's very important to begin training with mirror feedback, however it's also very, very challenging for the people to actually look at themselves in the mirror, once they realize or appreciate the degree of facial paralysis, it's very challenging for them to look at themselves in the mirror, but you get there.

>> And as I said earlier, I think our center does a great job in providing the psychosocial support that's needed in facial paralysis.

>>Because so many of our patients come from far away to the Facial Nerve Center for their therapy, we place a strong, strong emphasis on doing a home exercise program. We spend a lot of time, well over one to two hours, explaining the physical therapy exercises, so that you are very comfortable doing them at home. We provide you with an exercise video, with plenty of handouts and photos of each of the individual exercises. Each exercise program is tailored to everybody's individual needs.

>>We typically see people for their appointments about one time a month for up to 12 months, sometimes longer, to educate you on the progression of the exercises. We start you off with three or four exercises and ask you to come back in about a month and progress the exercises, so that you are reaching each of your individual goals.

>>As Dr. Hadlock said, we're a multimodality center where we work closely with the surgeons and Dr. Hadlock and I work very closely together. So after you have had your physical therapy we consider the surgery and Dr. Hadlock and I work very closely making our decisions together. Of course, you're involved in that decision-making process, as well.

>>Okay, next slide, please.

>>As I said, one of the most important things of our rehab program is to teach you about the individual muscles of your face. I feel a patient that is an active recipient of their program does much, much better. I love whether a patient comes in to me and shows the individual muscle on this diagram and says oh, Mara, this is where I'm seeing a little bit more movement. My ZYG, which is the zygomaticus muscle, I'm now starting to see a little switch in the movement of that muscle. I'm very happy to hear when patients are able to understand the anatomy that I spent so long teaching them. But I think once you understand the nuances of your face and how your face can move, your outcome will be much better. So I spend quite a bit of time teaching you the muscles in your face.

>>All rightee, next slide.

>>Secondly, the component of our rehab program is relaxation. If you have developed some synkinesis following your tumor excision surgery, I've devised a relaxation CD and I'm going to see if I can play it. If you can play it press that button see how it works.

>> <u>Kim Bischoff</u>: I'm not hearing anything here.

>> <u>Mara Wernick Robinson</u>: Oh, bummer, okay. It's a 10-minute audio relaxation, which guides you through the individual muscles of your face and teaches you how to decrease the tension in each of the individual muscles of your face. It uses guided visual imagery to help you to control the facial synkinesis. It's mainly for the patient who is experiencing synkinesis. Next slide, please.

>> Kim Bischoff: Having trouble-- there we go. Is that the right one?

- >> Mara Wernick Robinson: Next one.
- >> Kim Bischoff: That one?

>> <u>Mara Wernick Robinson</u>: Sure. The third component of the facial rehab program is to teach you how to massage your face on your own. It would be awfully nice if I was the one giving you the facial but because we see patients only about once a month so we focus the treatment on self-massage.

>>Here's one of the most common massages that we give to the cheek muscle. It helps increase blood flow to the cheek, it helps to increase circulation and generate the beginning stages of movement. We ask that you stick your thumb in your mouth, your fingers on the outside of your cheek, just below your cheekbone and gently squeeze and pull your fingers down to the corner of your mouth. You're applying firm, steady pressure, and for those of you that have undergone an acoustic neuroma surgery and placed your fingers in your mouth you will feel the tension in that zygomatic muscle groups. That is one of the mainstay massages that we teach people and has what I call the wow factor when you do massage your face. It helps to, as I said, increase circulation.

>>If you have undergone one of the facial surgeries that Dr. Hadlock described, this is a massage to do to that transferred muscle. So this is the area where the gracilis may have been placed, and we begin massaging that gracilis in the early stages to help with movement regeneration.

>>Next slide, please. Neuromuscular retraining, with mirror feedback, is used to promote small isolated movements that are slow, controlled and symmetrical.

>>Symmetrical is the buzz word. For people who are experiencing facial paralysis, we don't necessarily try to regain a full, big, toothy smile because that may not be realistic. We try and regain muscle movement but it must be balanced. We often use the term a Mona Lisa smile, so you're able to regain a smile, but with symmetry with both left and right sides of your face, I hope that is clear. Both before and after any muscle transfer surgeries, the goal is controlled symmetrical movement.

>> In addition to retraining the smile, we go through all of the expressions of the face trying to regain movement with mirror feedback by isolating each of the individual muscles. We refer you back to the diagram that highlighted each of the muscles, and how each of the muscles move and in which direction.

>>So once you understand that your forehead muscle or your frontalis is an isolated muscle responsible for lifting your eyebrows up you can look in the mirror and work on gaining that movement pattern back with our technique.

>>In addition, we use EMG biofeedback electromyography feedback, where we place small individual electrodes on the individual muscles and those electrodes provide you with an audio or visual signal, like playing a computer game. So the young children with facial paralysis can finally relate to my biofeedback machines and we provide feedback with the surface electrodes on each of the different muscles.

>>That's not designed to strengthen a muscle, biofeedback is designed to teach you which muscles need to be used to generate a facial expression. So, we would be placing the surface electrodes on your cheek muscle to alert you to the fact that your cheek muscle is beginning to move again following surgery.

>>I want to make sure that most people understand that we do not promote electrical stimulation. There is no research to support that applying E-STEM or electrical stimulation will regenerate the muscles, and it can be painful and furthermore there have been two studies that electrical stimulation can increase synkinesis which is aberrant nerve regeneration that can occur following acoustic neuroma nerve resection. All right, next slide, thank you.

>>So this is an example of neuromuscular retraining for the smile, whereby I was teaching this patient how to form a small symmetrical smile as she tries to regain the weakness on the left side of her face. She should be looking at herself in front a mirror.

>>Eventually we do move you away from mirror feedback because you can't walk around with a mirror through your life, but beginning stages of facial rehabilitation is doing a lot of mirror feedback, next slide.

>>In addition to the relaxation, and the retraining of movements in front of the mirror, we spend time helping patients regain the functional component necessary for eating, drinking, drinking out of a straw or drinking out of a cup, working on articulation and speaking, as well as expressing emotions.

>>And that is done with props, we work on drinking from a straw and eating certain types of food and teaching you how to regain the movement necessary for those functional movement patterns as well as compensate for those movement patterns.

>>All rightee, I think I'm ready for the last slide. Smiling is probably the biggest goal that most of the patients that come to see us at the Facial Nerve Center have. Most everybody state that their goal is to improve their smile.

>>I do want to stress that we all smile differently and while we encourage you to return to as normal of a smile as possible, you may need to remember that there is a new normal and we are here to help you to regain as much of a smile as possible.

>> <u>Kim Bischoff</u>: Well thank you very much, Mara. What a great program you and Dr. Hadlock had together there in Massachusetts.

>> I do have a question, here. Says what happens if the surgery is performed without the rehab program?

>>: That's an excellent question, we stress that you have at least two physical therapy sessions following your muscle transfer surgery. You just obtained a new muscle; we want to be able to teach you how to utilize it properly.

>> <u>Kim Bischoff</u>: Okay, I guess and then this gentleman is saying he's from the UK. And right now, I'm not seeing another question yet, although I'd like to give everybody just a minute because they might be typing something here.

>>Yes, here's another one that's just come in.

>> Mara Wernick Robinson: Great.

>> <u>Kim Bischoff</u>: It says massage, is that something we can do at home now.

>> <u>Mara Wernick Robinson</u>: It depends on what your problem actually is but I do recommend that the smile, the slide that I showed you, where you are massaging your smile muscle, you can place your thumb inside your cheek and what I recommend is you take the thumb of the opposite side, so if it's your left cheek, place your right thumb in your mouth and then place the fingers of your right hand on top of your cheek and gently squeeze your thumb and your fingers together, as you slide your fingers down towards the corner of your mouth. I recommend that somebody does that about 10 times, a couple of times a day.

>> Kim Bischoff: Okay now we have another--

>> <u>Mara Wernick Robinson</u>: It should feel a little uncomfortable, that's okay.

>> <u>Kim Bischoff</u>: Thank you. Here's another question for you. What are your feelings about acupuncture and increasing blood flow to the nerve?

>> <u>Mara Wernick Robinson</u>: My standard answer for that question is that the jury is still out. For every article that supports acupuncture there's a research article to support that it does not make a difference. I have not heard ill effects from acupuncture and a handful of patients say that it is helpful in relaxing but I cannot speak to the validity of acupuncture changing the state of the nerve.

>> <u>Kim Bischoff</u>: Okay, thank you. Here's another question. How long does it take a physio session to obtain optimum movement and symmetry?

>> <u>Mara Wernick Robinson</u>: I have a few patients that can obtain-- that can understand the program within the first session and I have other patients that take up to six sessions to learn. The average patient is four to six sessions.

>> <u>Kim Bischoff</u>: And then this is a good follow-up question to that. Do you offer special training to massage therapists?

>> <u>Mara Wernick Robinson</u>: We have-- we certainly have begun a facial rehabilitation training session at the Facial Nerve Center, whereby we invite therapists to spend the day with us and learn the facial rehabilitation process. We will have that available on our website within the next couple of weeks. We get requests for that very often.

>> <u>Kim Bischoff</u>: Here's another, how long do you have a patient try physical therapy before considering surgery?

>> <u>Mara Wernick Robinson</u>: That's my favorite question, I'm so glad somebody asked that. We would probably work with you for at least six sessions before you consider surgery. If you have complete facial paralysis, it's usually only one or two sessions because we could tell within one or two sessions if it's going to make a difference.

>> <u>Kim Bischoff</u>: Here's another one, dimpling of the chin after facial paralysis, what do you recommend Botox?

>> <u>Mara Wernick Robinson</u>: Dimpling in the chin is an example of synkinesis and Botox works beautifully on that spot. The injection is to the mentalis muscle.

>> <u>Kim Bischoff</u>: And then somebody else is asking is there a way that this could be done through a video for people that are far away using a video cam?

>> <u>Mara Wernick Robinson</u>: Unfortunately we're not allowed to do that because of liability and insurance purposes.

>> <u>Kim Bischoff</u>: And then there's another question, I'm not really sure if I have enough detail maybe you'll understand it. How do you spell the name of the muscle, you know which muscle she's asking about?

>> Mara Wernick Robinson: Probably the gracilis, g-r-a-c-i-l-i-s.

>> <u>Kim Bischoff</u>: She's saying in the Botox, she's asking the question in the Botox.

>> Mara Wernick Robinson: Oh, mentalis, m-e-n-t-a-l-i-s.

>> <u>Kim Bischoff</u>: Thank you, and let's see if there's-- there's one more here and I guess we'll let this be the last question for tonight. What is the maximum time overall to achieve positive results?

>> <u>Mara Wernick Robinson</u>: Oh, I have seen patients work for up to two-years before they've reached a plateau. I want to put in a point that the patients that put in the most time and energy into the process have the best results. That sounds obvious, but it's like training for an Olympic sport, it takes a lot of hard work.

>> <u>Kim Bischoff</u>: And absolutely some remarkable results that you are having out there. Well, I'd like to thank you very much, Mara, for giving up your time this evening and for everybody joining us here tonight. And we look forward to having additional webinars on NF2. Again thank you to the NF2 committee without that group of people this just wouldn't be possible tonight. Thank you everybody, good night.

>> <u>Mara Wernick Robinson</u>: Thank you.

(Webinar concluded)