

## **Transcript of Orthopedic Surgeries for Lower Extremity Hemiparesis**

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Thank you, I walked in here and I realized that there is an extremely dedicated, committed group of parents who are here, especially Saturday at 3 o'clock in the afternoon. I have asked the people in the hotel to lower the temperature to 15 degrees to keep you awake and also distract you from how beautiful it is outside.

So our hospital has got an epilepsy surgery program which I was very fortunate part of and one of the things when we started the program about 7 years ago was trying to figure out what's the orthopedic consequences of people who have hemispherectomy and we started do a literature search through PubMed, we found there actually zero articles talking about orthopedic aspects after hemispherectomy in children with seizure disorder and it is rather frustrating. So when you go and you bring your child to see an orthopedic surgeon for a consultation they're going to be faced with the same kind of information that I found on the internet, which is basically nothing.

So I want to try give you basically, in about 45 minutes or so, where we come from, where orthopedic surgeons come from when you bring a child to see them in terms of where our sphere of thinking is and how our approach is to a child. Now orthopedic surgery in terms of pediatrics is primarily dealing with the crooked child, so cerebral palsy and treating children who have got deformities of the limbs is basically bread and butter orthopedic surgery. Many orthopedic surgeons who train in pediatric surgery are very comfortable with cerebral palsy so may speak to you in terms of how you manage your child they're going to speak with a trend towards what they think about in cerebral palsy. So that is basically the reference point for which that is.

So I want to go through some terminology, some orthopedic terminology, I was asked to speak about hemiplegia. The hemiplegia we think about actually refers to a stroke where you're paralyzed and in children that have had hemispherectomies they are not really paralyzed; they're weak. So it is probably more fair to talk about what happens to our children in terms of them not being hemiplegic but hemiparetic which is probably the more appropriate term that reflects the weakness of purposeful movement that results after the surgery. Now we don't see this sometimes because the children are very spastic and sometimes that spasticity gives them some functional support to their leg. Whether or not that is meaningful motor movement or not, that's where the weakness comes in. So to be fair I think we're talking about hemiplegia we are really talking about hemiparesis. So you are going to see me talking more about hemiparesis rather than hemiplegia because that is kind of more accurate.

So as you know, spasticity really is a motor disorder is characterized by hyperreflexia. Reflexes are very, very active and you will notice that when you arrange your child's legs if you arrange them very quickly there tends to be a lot of reflexive fight as they fight against you but if you hold them slowly and stretch them they'll give and that's one of the hallmarks of spasticity is that it is velocity dependent. The faster you arrange them, the faster you stretch that muscle, the more it fights back against you and that's a function of the reflex arc that we all have in our spinal cords. In fact any dysfunction of the central nervous system will give you spasticity so this by no means is a reflection of just post-surgery but also can be due to either seizure disorder or if the child preexisting injury from an occiput injury or from seizure disorder and they have cerebral palsy, this also will give the same spasticity.

So we try to talk to people about spasticity, it's hard for us to describe it unless we talk about basically a muscular tug of war. So when you and I move our arms and legs we take it for granted that our joints move supplely, but that doesn't happen automatically. Actually what happens when we move our elbow back and forth one muscle has to relax and give for the other muscle to move the arm. But for somebody who's spastic that's a muscular tug of war where nobody wins and that's a problem. So rather than talking about people being spastic it's like the tone never gets any less, we are not really spastic we are hypertonic that's probably better.

This idea of hypertonic really is variable, it changes from moment to moment and day by day, your child will have good days, bad days, good moments, bad moments, it will fluctuate, it will never be the same any day or every day. Hypertonicity or spasticity is very much modulated by the child's environment and as you know if your child is upset, cold, hungry, tired or excited their tone goes up. It also as they grow and have a growth spurt their tone may get worse. When they go through puberty their tone will change but also if they are immobile, their tone will also get worse. Conversely anything that you can do to improve their environment will decrease their tone such as regular sleep, keep them warm, comfortable, well fed and also keep them mobile.

So of course, the worst thing you can do is tickle somebody who has hypertonicity because they can't pull away from you and the more they tickle them the more their stress goes up and the more they can't move, so it is pretty cruel to try and tickle somebody who can't pull away. Which is one of those things.

But, when we sit in these chairs and when I stand, you have to understand that there is a partial degree of muscle tone that you and I exert just to keep our heads up, to keep our trunks up, and keep our legs locked and that not only for us only for us to be able to stand and sit and hold our heads up requires partial relaxation of our muscles and when we have a problem with that tone this is where things go awry in terms of your child's ability to stand and walk after surgery.

You combine that with the fact that your child is growing, now that gets even worse because you combine hypertonicity with weakness and they grow, they start getting contracted, and the faster they grow – kids have got 2 growth spurts, one at around age 5, one age 10, the more their contractures will get worse and you should anticipate probably that they may actually have 2 periods of time where they actually seem not to respond at all to physical therapy primarily because they are just growing so darn fast.

In fact, as a child grows the child needs about 6 hours of regular stretch to stretch their muscles, so the growth plate to the muscle is where the tendon connects to the bone and that adds more cells to the muscle in response to daily movement and daily stretch and people know that you need about 6 to 8 hours sustained stretch a day to prevent contracture. What I am talking about is that in order to keep up a child's growth with their skeleton, you've got to have sustained stretch on those muscles for 6 to 8 hours a day and if you don't do that then what is going to happen is you have a net loss of the ability for the muscle to keep pace with the bone growth, you start getting tighter and tighter and tighter. So, that's one of the challenges to deal with especially since we don't have 6 hours a day to stretch our children, how do you go about trying to get that 6-8 hours of stretch so you don't have to think about contractures as they get older.

So I want to focus really most of my talk and talk about the child who has hemiparesis who walks, because I think that is probably what's most important. I just want to briefly review that when you take a look at the priorities of a handicapped child, walking really is the last of 4 things, it is really more important to focus on their communication. I just stepped in on this very nice talk about communication, daily living activities and mobility

and walking really is the last of 4 priorities. I think it's important to recognize that. For me as an orthopedic surgeon I probably play the smallest role in the care of your child compared to all the other specialists you have seen today.

If you think about what it takes to walk it's very interesting: You have to be able, number one, to stand. You have to be able to stand well without using any support. Number two, you have to be able to pick up one leg because when you take a step you've got to be able to stand on one leg for one or two seconds or so as you swing a leg forward. You have to be able to pick your leg up enough and bend your knee and bend your hip and pull up your foot so your toes don't drag. You have to be able to bring your leg forward enough so you have a decent stride otherwise you take these little small, skipping steps. You have to be able to put your foot down in a position where you have balance and stability and you have to be able to do this over and over again without getting tired. So it's one thing to be able to stand and another thing to be able to walk and that is a huge quantum leap in terms of mobility because there is a lot more to get a child to walk as opposed to standing.

So the problem of course is that after a hemispherectomy we will lose a lot of selective muscle control as part of the surgery as well, we will also have those abnormal reflexes which affect our gait patterning, some of those reflexes may actually precede the surgery, plus the decreased balance that we have as a result of surgery affects our ability to stand on one leg, to pick a leg off the floor and swing it forward and that's a problem.

It's funny you know, because when you talk to an orthopedic surgeon we will focus more on your child's legs and hips and you will seldom hear us talk about your child's hand and arm and I'll tell you why. Orthopedic surgery traditionally has fallen into spine, foot, leg and then hand as an afterthought. In fact, for people who do a lot of this there is a separate sub-specialty of orthopedic surgery which is just hand and you may find that actually, when you see an orthopedic surgeon if they see that your child needs something that involved improving the function of their hand they may send you to another specialist. By and large the reason why that is is because God gave us 2 hands and if 1 hand is weak then the other hand is usually the dominant arm and most children will use the weaker hand as a support or paperweight or something to push against. The indications for us to intervene in terms of a child's hand are actually pretty minimal; that is, if there is an issue with hygiene, skin breakdown or function, that's when we interfere and try to intervene but aside from that we leave a lot of the therapy to therapists and if there is a need for intervention most of the time unless your surgeon is additionally qualified in hand surgery, you may get sent off to another specialist who does pediatric hand surgery.

You have to understand of course, that the gait problem that is going to be in hemiparesis is primarily the central nervous system but also be can't forget there is also tone. We talked a little bit already about these issues about tone and balance and coordination but also you have to understand that as your child grows and gets heavier and taller they're a moving target. So to broadly talk about what we do in terms of orthopedic surgery, think about problems with soft tissues, problems with the bones, the shape of the bones and then problems with the joints. Then based upon those problems you can treat them with surgery or braces or physical therapy.

So this is a caricature of the typical posturing of a child who has spastic hemiparesis, you see the typical postured arm with the bent wrist and the bent elbow and normally they would walk on their toes or maybe on the outer border of their foot, they may drag their foot a little bit and I think this is exaggerated picture, I think most children hide this very well because they know what they do. My experience is that a lot of children if they are coached very carefully will walk quite well. When you see this is when they're tired, or when they run too much,

or at the end of the day or they are upset, that's when the posture occurs. That's when you see that it's worse. This is typical of what you see in somebody who is at their worst in terms of spastic hemiparesis.

The nice thing about these children is that almost all of them will walk regardless, which is good and most of the issues which will affect them as adults is partly to do with the arm. When you take a look at adults in the community who have spastic hemiparesis either from cerebral palsy or from a stroke, you don't really focus on the fact that they have a slight foot drag. Most of the time we as adults, we see that they are posturing their arm and that gets to be a little more of a social issue which we coach the kids and the parents that your child will actually find ways to accommodate for that as they get older. Such as when they talk to stranger they know they'll posture, they may just subtly put their arm over their wrist and hold on to it. Or they may hook their thumb in their pocket, or put it in the back of their jeans or something like that. These are skills which children learn by themselves, they may be coached, they may be taught but it is really more of an upper extremity issue which affects these children as adults not so much their feet and their legs.

So, here are the options available to an orthopedic surgeon: We can send them to physical therapy; we can prescribe a brace, or operate. That's the 3 broad groups. Really, it is more well defined in terms of their age. Generally speaking for children who are less than 5 there really is no role for surgery. The reason why is because they haven't had enough time to grow yet to the point that they develop a contracture so they are eminently treatable without surgery, primarily with physical therapy and bracing. So when I see a child that is post-hemispherectomy and they are 3 or 4 years old I am a non-surgery kind of guy.

In fact, when you talk to surgeons you will find that surgeons fall into 2 groups: They are the bracers or they are the non-bracers, and depending on how you feel about that you may find that you may want to swing from one surgeon to another. Some surgeons will say, 'well if you brace your child they'll never develop a deformity and that will protect their joints', the counter argument to that is that if you always brace your child they will never be brace free and they will always be brace dependent, so what do you really want for your child? So, that is a philosophical argument and there is no answer for that, you simply have to believe and see what your child is capable of and go from there.

From age 4-8 that's where most of the big work comes for me as an orthopedic surgeon, I'd say maybe 4 to 10 or so, that's when we really do a lot in terms of treating these children, primarily because they have had their first big growth spurt and now they start having these problems which occur when they start growing and they don't stretch enough, and they start having problems. This is when you do all the surgeries; this is when you do the bracing. So bracing does work when children are growing because that's how you get the additional 6 hours of stretch is you actually hold them in a brace that keeps them in the stretched position and that's one of the reasons why there is a feel that people say that people say that they should brace kids more not less.

After children get past age 10 or 12 or so we don't really talk too much about intervention, more accommodation, because at this point the ability for neuroplasticity to compensate for any post-surgical deficit gets less and less and less and now we begin to shift towards what can we do to improve their function but what can we do to improve their ability to work with what we have. So you may find that as your child gets older that some of your therapists may begin to slow down their visits, you may the insurance companies begin to fight more in terms of providing more approval for therapy simply because they've seen, at least from the cerebral palsy data because that's all we really have, is that a lot of this intervention doesn't really work once the kids are in their teens and this is the reason why.

So, let's talk about bracing. When you talk to orthopedic surgeons they will use words like HKAFO, AFO, KFO, RGO and you wonder, 'what's with all the O's'? Basically these acronyms talk about the joints which are immobilized. So the A in the AFO is the ankle, F is the foot, the K is the knee, the H is the hip. So you just kind of go from the head down to the foot. So if you've got a brace that goes from the hip down to the feet it is going to be a hip, knee, ankle, foot, orthosis – an HKAFO. If you have an AFO, that's an ankle foot orthosis. If you have an SMO – S is Supra Malleolar which is basically a high top orthosis and that's how we talk about that. So this brace that you see here control the knee, the ankle and the foot, so this we call the KAFO. We don't really prescribe these things anymore because they are heavy and they're clunky and children don't want to wear them and it slows them down, it rips up your couch and they're horrible. In fact, most people now say that with a good, smaller brace that does everything you can do with a bigger brace so it's really not very useful unless you use it at night as a splint. I think a lot of therapists will recommend a night splint for early contractures primarily at the knee for the children to wear because it allows you to get some passive stretch of the knee as the child sleeps. So if you see somebody who talks about one of these long braces, you've kind of have to say, 'well why is this better than a smaller brace'?

So this is a smaller brace, it's called an AFO or ankle foot orthosis and this is 99% of the braces that you'll see children wear and it's really evolved tremendously as we've known more about how the ankle works and how it's coupled with the movement of the hip and the knee and if you do something to the ankle you can actually do a lot to actually effect how the knee moves and how the hip moves. This is the brace, this is made by Cascade, and these are light materials. Now you don't see the kids transitioning to hard fiberglass materials or a brace with a hinge until they are much older, why? Well, because they outgrow these things and these things are expensive. Number two, they're heavy as you get more sturdy, and number three, when you wonder about where does your child flex when they walk, it actually bends through the bottom part of the hinge right here though actually it will flex through the middle part of their foot. That'll be the hinge for their ankle. We can do that for a lot of children simply because it is hard to find shoes that fit over a bulky brace with an ankle joint on it so when you somebody who describes an AFO that's rigid you will find that oftentimes your child [---] won't be a hinge because it actually makes it heavier, makes it more bulky and kids actually don't like wearing them. When they do incorporate a hinge a lot of times the hinge will have a stop that keeps your child's foot from dropping too far because toe drag is usually the biggest issue although those hinges tend to fail a little bit.

So this is one of the hinged AFOs. As you can see there really isn't a hinge per se, there is more like a flexible elastic strap which has got some obsolescence and wear and tear, it's going to fail, but still it's light, it's not very bulk and of course when your child outgrows it in a year and half it's expendable. This is an example of a hinged AFO with a nice little stop on the back that keeps a child from dropping her toes too much. There's a balance; when you prescribe a brace for a child you want to say, 'well what am I trying to achieve here? Because if I don't want the child to drag his foot then I give him a brace which doesn't let the foot drop down, how is he going to be able to push off when he walks heel to toe'? He'll start walking like a little old tin man. That's one of the problem we try to find out as orthopedic surgeons what is the right mix for a child in terms of what's too much stability and not enough flexibility and that's really the struggle, we try to find a balance between flexibility and stability when we brace a child.

These AFOs work great especially when it comes time for your child to go upstairs because that's typically where children trip, they can't pick their foot up enough if they're tired. This does some good stretching for the calf which helps fight their ankle contractures and thus try to address that stretch reflex that makes it more spastic. So,

the ideal brace would be one that limits your range of motion just enough to keep you from dragging your foot but not to a point where it limits your flexibility totally. If you think about how you and I walk, we pull our foot up our brains are programmed to bend our knees back. When we push our foot down, we're programmed to extend our knees and that's called a coupled motion, that's one of the higher levels of neurological patterning which a therapist works very hard when they try to get the children to actually work not in terms of actual single joint but multiple joint therapy to get that couple heel/toe, ankle/foot motion going on and then when they get good at that then they start talking about coupled motions, they talk about motions between the hip flexing, the knee bending and the foot going up at the same time. So you have to think about how their brace affects that.

You may hear about manipulation and splinting in casting. The whole idea of course is that this provides sustained stretch and if you provide that stretch 24/7 then you will get that muscle to add more cells to the end of the tendon which makes the muscle longer, we can change those casts every week and you begin to make some incremental improvement in the child's contracture. That works great if your child has a mild degree of tightness, it doesn't work very well if your child is really, really stuck because sometimes deficiency in terms of length may be in the span of 3 or 4 inches and it is not feasible to actually try to stretch a child because it causes a lot of pain. In fact, if you have a child who doesn't get better with one or two casts it may actually give some false hope to the parents. It is really best for those children who actually do have a contracture and they are not one of these weird variants where they have more of a motion disorder.

It does work great for about 6 weeks after the last cast and typically what happens is that children outgrow that correction and they are tight again so I don't see serial casting or manipulation as being a cure, I think it is something that buys you time if you need to buy time for another issue. So if your child for some reason is not stable enough to undergo surgery to lengthen a tendon you may want to try serial casting. Or if for some reason they don't do well with anesthesia or some other issue then serial casting may have a role for that. You have to be very careful though because I've seen bad pressures ulcers - if you push a child very, very hard, they get pressure sores from the casting or you stretch a nerve, now they've got foot drop because you've stretched a nerve. In fact, I've seen folks who have actually broken children's bones. Yes ma'am?

*Audience: Sorry to interrupt but this is a sore subject for us because our daughter's arches, basically they collapsed due to over casting.*

Correct.

*Audience: And we now have to have a number of orthopedic procedures to repair that. We just had a tendon lengthening and we were so trying to avoid that.*

That's correct.

*Audience: I want to warn people to be aware of that.*

What happened? Can you say what happened?

*Audience: Well, so what happens is that for a child who can't pull their foot up because they are tight in the calf, if they have no flexibility in their ankle joint they'll turn their foot out and pronate their foot and they roll onto the inside of their foot. Now what happens is that, that's how they get their additional mobility and if you keep on*

*doing that you actually get that as your primary problem and to fix that now you have to fix the tight Achilles tendon and then the fact that now their foot has turned out. So when you and I as adults get tight in our ankles a lot of times we will also pronate and turn out as part of a problem we have as adult with plantar fasciitis and heel spurs, but in a growing child it's much worse and this is a problem.*

So to your point, I think that somebody who is doing this needs to check your child pretty regularly to be sure that they are not creating a secondary for them. We do a lot of Botox injections for these kids as outpatients because it lets you decrease the spasticity for about 3 or 4 months, it lets you probably do a little bit more of the serial casting. So if you are a neurologist or an orthopedic surgeon who feels comfortable with Botox injections we do that a lot to try to keep these kids, especially kids who are less than 5, because they do so well.

Surgery, this is where we come in. I think it's important for you to understand that we as orthopedic surgeons really try to not talk about surgery every summer for your daughter, or every Christmas, because we understand that for every surgery there is a long recovery. For every surgery there is 6 weeks in a cast, for every surgery there is a loss of your motor milestones, so we don't want to do that and your surgeon may say, 'listen if we are going to fix the ankle, we may actually want to fix the hip and the knee as well'. We're not trying to make money so we can pay off our cars we're trying to actually say that this is actually better procedure for your child because it is one recovery, one convalescence, we don't want to fall into anniversary syndrome; 'oh it's summer time, let's fix this, it's summer time, we'll plan this for next Christmas'. That's not what we want to do we actually want to work the entire extremity at one time to fix it all at once and also we have to be pretty realistic in terms of what you can expect out of the surgery, that's important.

For instance, a small subset of children who aren't spastic they actually have movement disorders, they're athetonic or dystonic. Those kids we can't do orthopedic surgery on because their motion pattern changes by the moment and when you do surgery like this you have the really bad effects and you don't actually get the kind of affects you want. So that's a real problem.

So the principles I use is that if you see your child is beginning to have problem try to relieve it in part with physical therapy and a brace so you can stall surgery until at least after the first growth spurt, so if your child is 3 or 4, beginning to have some problems, really ramp up therapy and bracing, try to get past the first growth spurt, then we do surgery because you know they will at least get 4 or 5 years out of the surgery.

The other thing is that those children that are less than 6 or 8 really don't do very well with physical therapy, especially physical therapy after surgery so you need to have a child who is mature enough and has an attention span long enough to actually work well with a therapist. So it is wise to delay surgery until that age. You also have to understand too that sometimes the bones are actually affected and we need to adjust those as well.

So if you have Gait Lab that is close to you in your State, I recommend you get your child analyzed at a Gait Lab. I think [inaudible] because a lot of this in terms trying to figure out what is bad muscle, it is very hard to figure out even if you are somebody who watches your child over and over again, sometimes you actually have to do the high speed camera and endomyelography to figure it out but [---] as some of you may have heard may not be reimbursed by insurance, may not be available in community, so it is nice to be able to have it if you can actually get yourself analyzed at a gait lab.

So the principles are we talked about, for instance, correct everything on one leg at one time. Do it all in one stop and if your child has both legs affected we are going to everything one time, even though that means they are spending huge amount of aftercare for 6 weeks after surgery, it's better in the long run to put your child through the surgery just the once.

Here's a big thing: How do you know whether or not your child simply has hypertonicity or true contracture? So again, if your child just has a muscle which is spastic you'll know because when you put stretch on their limb after about 10 seconds it'll give and you'll get all the flexibility back. That's spasticity. That doesn't mean you'll need surgery. You probably can feel [---] it's when children have a contracture where no matter how much you put stretch on their joint it never gives. That's when you need surgery. Sometimes it is hard to really know whether or not your child has 50% spasticity in a muscle/ 50% contracture, so there are times where I may say, 'well let's try Botox and serial casting for 6 weeks', and if your child still doesn't pull all the way up then probably it's a contracture and you will need surgery. But I think that's probably a better approach than just saying that they all need to [----] spasticity and surgery. There is a lot of ability for us to actually use gait lab to figure out exactly where the problem is in terms of spasticity and contracture.

Anyway orthopedically we deal with either we lengthen muscles or we transfer muscles or we cut muscles. When you lengthen a muscle what you are trying to do is you're trying to restore the length to where it's supposed to be and that's it. Also what happens is unfortunately it also weakens the muscle because muscles have their own resting length which makes them work at their maximum degree of strength and when you make a muscle too long it takes about 6 months for the muscle to get back to where it was before. That may be good if your child walks on their toes and all you want to do is not have them walk on their toes in which case being weak in a calf for 6 months will not be a bad thing, but if your child is walking and you're wanting surgery to lengthen their hamstrings well that means they won't be able to bend their leg back or bend their knee for 6 months, that may mean that they won't want to walk as much because they can't support their knee which is a big deal.

This is an example when we do lengthening, fully extended, this is how most people do it, if you take a look at the figure on your left what's been done is that 3 little poke holes are made through the skins and the tendons cut halfway through the 3 different spots. If you notice the tendon's only cut halfway through on the inside above and below the cut in the middle, the reason why is because no muscle fiber actually gets cut more than once if you do it this way so you only cut the muscle once and when you stretch the ankle what happens is that those muscle fibers will slide and [---]. It is a very delicate surgery because in terms of recovery there's just 3 little poke holes at one stage and there is really nothing in terms of scarring or blood loss and you can even get probably about 20, 25, 30 degrees per inch of surgery. The problem is you can only do it once; when a child heals they heal with scar tissue and now if your child needs another surgery we can't do it anymore because [---].

I used to tell parents that if we do this surgery for your child expect 4 or 5 years, maybe 6 years, but they will probably outgrow their surgery when they have another growth spurt before puberty in which case I would expect that they may need to have this done a second time but once you have this done the second time when they are 13 or 14 it probably won't need to happen ever again as an adult.

*Audience: So what if our kids go into very early puberty? So my son, he had bilateral foot surgery and now the whole hamstring is in contraction, he's a Tanner stage IV, he's [---] he's only 10, what do we do, do we wait for the growth plate to stop? I don't know what to do.*

No, I don't think so, I think that [---] really important to [---] the surgery, there is really no merit in waiting until they are old enough because if your child's having a functional problem and nothing else works then that is the time for the surgery. I think the overall goal is [---] function and nobody said that it will [---] causes the spasticity to get worse so the last thing you want to do is to have your child not be able to be mobile, let them [---] with hemiparesis that's actually worse [---]. That's a good point though.

*Audience: Can we ask one more question?*

Yes.

*Audience: If you said you can only do the surgery once, once they hit puberty and they have a second growth spurt what is the second surgery?*

The second surgery involves an incision that is basically 2 inches long; we physically cut the tendon in two so we lengthen it. So it's still the same procedure but it's a little bit more surgery, the recovery is still the same, it's just that now it's a bigger incision. But there's a point of the initial recurrence for a point that every time you do more surgery you create more scar tissue; every time you cut scar tissue it heals as worse scar tissue. That scar tissue doesn't contract, doesn't stretch, it actually makes you worse so that's why we're very sparing when it comes to leg lengthening surgery because we know that surgery causes scars, scars affect function so we don't go on to the point where your child has tremendously shaped legs but nothing actually is strong when he actually moves. We really want to be very judicious when it comes to leg lengthening surgery.

The second thing that we can do is we can actually transfer muscle. This is typically in children who have spasticity around their knees where they either don't bend their knees when they walk and they walk like the tin man, or they never get their legs straight when they walk, they always crouch. What you are trying to do is you are trying to transfer a muscle that works to replace a muscle that doesn't work. Typically the muscle that doesn't work is the back of the knee, we'll take muscle from the knee and you'll move it to the back and vice versa. It works well so long as you are very, very confident that you know that the muscle you are transferring actually isn't spastic and that's difficult to assess.

The other problem of course is that the child has to be able to move that muscle and control that muscle volitionally in order to be able to train their brain to work that muscle, otherwise what happens is you just create a static bridle that keeps your leg from moving. The other problem with muscle transfer is that every time you transfer muscle you also lose one grade of strength. So if we graded strength [---] from 0 – 5, so if you have a muscle that is pretty strong and your transfer it, you will only lose one grade strength you never get that strength back. We do this a lot as well around the hip.

The last thing we do is tenotomy and I think maybe [---] and when you cut it in half what you do is you're releasing the tendon and then the tendon doesn't work anymore. It's got some advantages and disadvantages. When you cut the tendon in a growing child the tendon actually grows back together if you keep the ends still and you immobilize it for 6 weeks. So it may seem really horrible to think about somebody cutting your tendons in half and [---] but if they do it in a such a way that you preserve certain [---] that tendon and keep the child's leg basically immobilized, that gap will fill in the [---] and in time those 2 ends of tendon will actually be continuous again. So for some of the muscles that we do that actually is pretty viable especially the muscles where the tendons are too small to actually make those few little cuts, we can simply cut them in half and immobilize them.

There are some muscles where there is no tendon, the tendon is actually inside the muscle, in which case I would simply cut the tendon within the muscle and now the muscle fibres to stretch and everything heals and that's particularly common around the hip as well.

The problem when you cut a muscle and there's an old term that I was taught: When you deal with a child with spasticity and you cut one spastic muscle you may find that you've also uncovered another spastic muscle that you never saw that pulls them back the opposite way. So spasticity masks spasticity which is what I was taught to say. So if your child, for instance, crouches because their hamstrings are tight you may actually not realize the fact that when you lengthen their hamstrings their quadriceps are very tight and now their legs are too straight, so now you start chasing yourself trying to figure out exactly what is the culprit, and that's one of the problems.

Finally, we talk about bony procedures: This is typically more exclusively for the hip and the thigh problems. They fall basically into 4 different choices. Most of the issues we deal with in children who need this is usually osteotomy, we actually cut the bone and we reorient the balls so it goes into the socket and you put a plate or a screw in place. You can see an example of somebody who has had this, and they'll put a plate and screws in and a lot of these actually are great but in children they require 6 weeks in a cast and the 6 weeks in the cast is necessary because those plates aren't strong enough to withstand the forces of your child's spasticity or their body weight and we need the cast to help the bones heal without things coming loose.

The other reason why is because children are oftentimes extremely painful unless they are kept immobilized in the cast. The cast gives you that circumferential splint which keeps them comfortable. The bad thing about the cast is that they are also severely stiff and very weak after they come out of the cast and many times by the time you've got them back to their base line, they are now just as tight as they were before you started and this is the problem when you deal with the teenager who needs orthopedic surgery. Now, remember I said that when you're 10 or older we generally don't do orthopedic surgery, why? Well, say your 4 year old child needs surgery for their hamstrings. It is easy for you to care for them in their cast because they are light, you can pick them up, you can move them around and of course after they come out of the cast it is very easy for them to bounce back and regain their flexibility and mobility. What if your child is 16 and they are 150 pounds and now they are in the same cast? All of a sudden – woah – you can't pick them up, you can't put them on the toilet, they won't fit into your car because they are straight and once he comes out of the cast he is so stiff and so weak he may take 9 months to get his strength back and in that time he stops walking, he sits in his wheelchair, by the time he gets his strength back he's tight in the knees again. That's the reason why pediatric orthopedic surgeons will try to say that when you child is a teenager we're not really talking about trying to get them straight again, we are trying to make them more functional with what they have simply because the cure is worse than the problem in a lot of these issues.

This is an example of a dislocated hip which has become arthritic; it is basically fused to the pelvis. There is no flexibility in this at all and sometimes the only thing we can do if your child actually has arthritis in the joint is to cut the bones apart, put them back in a functional position and fuse them back again. This is typically in an older child who has had a foot problem where the foot's turned out, now it's not stretchable, now you say, well I can fix your child's foot but now we are going to have to start fusing joints together. It's one of those things: Orthopedic surgeries are a balance between flexibility and stability. You and I function in perfect balance, we are just as flexible as we need to be and just as stable as we need to be so what happens when your child has a problem? Well, they're hyper flexible but they are not very stable. What happens after orthopedic surgery, you may be

hyper stable but not flexible and all and this is the give and take when you think about this which is a problem. A lot of children if they have a problem with this we actually recommend just removing the ball of the hip. This as you can see is a tremendous picture because the total ball hip is just destroyed and there is bone spurs and everything. You see I've put joint replacement in parenthesis – the reason is that you don't do joint replacements in children because they simply wear them out and they'll destroy them so we try to delay any type of joint replacement surgery until they are hopefully in their late teens or early twenties when they are smart enough to realize that they can't try to wear out those joints. So totally hip replacement really is in parenthesis because you can't do it in an active, young individual, they simply don't last beyond 4 years.

So hip problems are few and not very common after hemispherectomy but again if you've got a problem with one hip – one hip's tight – usually the other hip is tight in the opposite direction and when you work on one hip and you make that flexible it's usually the other hip now that's tight. So one of the biggest thing is that you may have to actually think about when you do one hip you may have to do hips so you balance the soft tissues. We don't really do a lot of these surgeries because a lot of the problems they have with the hip are actually more dynamic, they are not static, which is a big deal.

We talked a little bit about some of these surgeries already where you can cut the tendon, transfer tendon, but most of the time your surgeons may say we should probably do both sides because if you just do the side that's bad the other side will actually get worse and that's the reason why.

Again, gait analysis is important because of the fact that multiple joints work together. So the hip and the knee and the ankle work together as a trio and if you think that your problem is just a tight knee and they can't get their leg straight it is probably a little more sophisticated than that and the problem is that if your child crouches and he crouches like this, how do you know that it's not an issue that their quads aren't strong enough? You may assume that maybe just their hamstrings are tight but maybe their calves aren't strong and because the calf is not strong enough they can't point their feet down so as a result they sag in their ankles so they have to bend their knees. Or maybe their hips are tight and because their hips are tight now they can't get their hips straight so they have to bend their knees otherwise they'll bend forward at the waist. So these issues become very vexing when you start talking about that, which is a big deal.

So typically stiff-kneed gait is one of the things that we look for in children who have hemispherectomies. When you walk, does your child actually bend their knee when they are picking it up and swinging it through the air? That's the biggest thing. If they can do that, that's great, if they can't that's the biggest reason why the children drag their feet on the ground. It's because they don't bend their knees when they swing through the air. There is not a brace that works to help your child bend their knee when that's in the year because all braces only work when a child's foot's on the ground. So that when you start talking about muscle transfers to help bend the knee during swing phase rather than bracing.

As you see what happens here on the figure on the far left side, is that the muscle is actually cut right here, it's actually transferred to the back of the knee so now when the child tries to straighten the leg that one muscle actually pulls the leg back, and that's called a rectus transfer. The reason why that works is because there are actually 4 muscles which comprise the quadriceps that's why it's called quadriceps, so 3 muscles left behind is satisfactory. So you can actually do this and it works well.

This crouch gait issue is the biggest thing that actually haunts us in terms of trying to figure out what's what. So as you see, knees are bent, hips are bent and it's a very hard position to try to walk long distances. If any of you have actually tried to walk without lock on our knees, it is hard to walk without locking your knees, it's hard to stand all day without locking your knees, it is very, very tiring so if you can just get the knees to come straight and the child to lock their knees it increases their endurance tremendously. The surgery for that actually is to cut a length from the hamstring tendons behind the knees to get them straight. It works very well, the problem is of course, that these muscles tend to get tight again as the child grows and typically we warn the parents that they will probably have to be done again in 3-5 years.

The problem with this surgery and most surgery in the legs is that each muscle in the leg doesn't just cross one joint. Each muscle in the leg crosses 2 joints; some muscles in the leg cross 3 joints. So now when you cut the muscle that makes the knee bent like the hamstring, that muscle anchors to your pelvis and that muscle is supposed to keep your pelvis straight so you can stand up straight. So what happens is if you cut the hamstring tendons so your child doesn't crouch, now nothing keeps their pelvis from tilting back and now they stand with their butt sticking back and now they start walking like this which is a problem when you do the surgery.

So when you start talking about why does my child crouch? You have to ask yourself well is it because their hips don't come straight, or their knees don't come straight or their ankles don't push down, and this is an issue. You need to really be careful when you analyze these kids because you need to avoid these problems when you do these surgeries.

Alright, let's talk about the feet. This is where 99% of the post hemispherectomy kids have problems. They don't really crouch too much, those are really minor issues, they very seldom have any hip problems at all, it is really the foot and the foot position. I've been fortunate enough to see every single hemispherectomy patient that has been treated at our hospital for the last 5 years and we've been watching them every year with x-rays and evaluating findings and I've done very little in the way of any other surgery besides surgery to the foot and ankle which is really, really good. These are the easiest ones to hide and mask when the child wears big shoes.

So a typical story I get is that – 'my child wears shoes and he doesn't walk on his toes any more'. Well, how do you know he is not walking on his toes inside the shoes? That's the problem. So what constitutes a good looking foot? Well for me as long as the foot's flexible and it's braceable and it's flat on the ground, that's a good looking foot. I don't care if it turns out or turns in a little bit as long as it is flexible and it's braceable and it's flat on the ground, that's a good foot. That's a little hard to convince some families who want a perfectly normal foot, in which case we may have to tell them about being a little bit more realistic in terms of the expectations because you can do a lot with a foot that's flexible but you can't do a lot with a straight foot that's stiff, that's the problem.

So we do a lot of tendon surgeries and you may hear people talk about these surgeries called a SPLAT or a SPLOT surgery. So if you hear the doctor talk about 'Splat' or 'Splot', they are talking about taking a tendon, splitting it in half (which is the SP) and they are transferring it to another part of the foot. Typically what happens when you split a tendon, you'll transfer a tendon through the bones to the front of the ankle to give strength to the opposite side of the ankle. It works quite well for a child who has got just this problem and when done well it is a terrific surgery.

You can also do surgery for the same thing by splitting the muscle on the back of the ankle – that's called a SPLAT. So this muscle here originally fixes to the big toe and it pulls your foot up. Now unfortunately because

it attaches to the big toe it also turns your foot onto its side when you pull your foot up. Now with you and I it doesn't happen because we have other muscles which actually keep the foot from turning onto its side. That muscle doesn't work in children who have hemiparesis so what we'll do is we'll split it in half and transfer the other half to the outside of the foot so that now it pulls just like a stirrup.

*Audience: Are you speaking about a dropped foot?*

Correct.

*Audience: OK, that's what my son has [---inaudible] is the surgery, is that an option?*

It would be an option. The big thing is can he demonstrate that that muscle actually works? So that's biggest thing is can your child demonstrate that they actually have control of that muscle volitionally to make it pull up and that's the difficult thing. A lot of these children may not have very good control of the muscle that you want to transfer so if you transfer it does it actually function to pull your foot up, or is it more just a static strut to keep the foot straight? Now this surgery does work well even as a static stirrup, even if it means that your child is able to have a foot that is straight that doesn't need a brace, it actually works very well.

[---]

It'll help with that ankle. So we talk about doing this to preserve mobility but sometimes just to get your child so that they are more functional without a brace, this works quite well and this is for drop foot, it's a drop foot surgery.

So this previous surgery that I spoke about here is a surgery when your child walks on the outside of their foot, and what you are trying to do there is trying to keep the foot straight. The SPLAT surgery which is split towards the interior is the front of the foot.

So that's basically what we talk about. So what do you do? The big thing of course is that if their foot's flexible then all these surgeries will work, if their foot is stiff and nothing makes it move then it is probably not a muscle problem it is usually that they are arthritic. Now you need to have a bony surgery which is going to be some kind of a fusion of the foot. So again, if the foot is flexible you're terrific; if the foot's stiff and it doesn't move and it is really in the bones then all of this orthopedic soft tissue surgery doesn't work, they will probably need to have the bony surgery and that would be a fusion surgery, that is probably what will be told to you.

Toe walking; a lot of kids walk on their toes. What was your question in the back?

*Audience: I was just [---] something we should expect as matter of course for a hemispherectomy or if there is a need for orthopedic surgery.*

These surgeries are very rare and I am talking about them only for completeness sake, they are not very common. The biggest surgery we do is just to lengthen the Achilles. The lengthening of the Achilles addresses probably 90% of the issues that we see in post-hemispherectomy kids.

[---]

Are there any physical therapists here in the room? No? There are great physical therapists who are tremendous advocates for a child, they are the liaison between the surgeon and the doctor and a family because they understand both sides, and they are the person who is the cheerleader and the spokesman for the patient. Then there are the 'physical terrorists' and the physical terrorists are the ones that do a lot to unravel some good work and the reason why I think both therapists exist is because there is not a lot of good concrete data that shows what works in physical therapy. There is a lot of physical therapy data that shows that this therapy works good in certain people, and the issue is, is that if there are 15 different ways of physical therapy what it means is that no one really knows what's the way to fix it. If there is only one way to fix a problem then I think people have reached consensus that that's the way you fix it. But anytime you see anything in medicine where people have 15 different ways to fix the same problem, what it means is that nobody knows what is the way to fix the problem. The only way to really know what's the best way to think about this is to actually say where is the peer reviewed literature that shows that there has been a controlled study that's done with thousands of kids, you can actually say there has been a statistically difference between the trial group and the control group. That study was done in 1980s and was published in the New England Journal of Medicine and it showed that there was a questionable effect of physical therapy compared to kids who just had regular play and exercise. I said this about 10 years ago and I almost got lynched and I say this very carefully because physical therapists are a tremendous help for us but as consumers you have to be very conscious to ask the question, why is this necessary? What are you trying to achieve? And what is the science, what is the research that proves that this actually is worthwhile? And if you find a surgeon or a therapist that can't cite for you, here this is the paper, this is the study or this is the text book, then you have to say well, is it just anecdotal experience that you're on? If that's the case do we really want to treat children with anecdotal experience? I don't know, maybe not. That's a problem.

So to answer your question about the splinting at night – there is no harm in splinting a child a night because they are asleep and if it's passive stretch – remember you need 6-8 hours of passive stretch a day, then that's an easy 6 hours. So night splinting is awesome so long as your child wears a splint. If they don't wear the splints then you have to duct tape the splint or creatively....that's where serial casting works. Serial casting basically is 24/7 splinting with perfect compliance, that's the leap from splinting to casting.

Anyway, this is basically the lengthening we do for the Achilles; you can see how we cut it in 3 different spots and it works pretty darn well so long as you don't over lengthen it. If you over lengthen this muscle what happens is now they can't actually stand on their toes and when they stand they actually crouch because their foot goes all the way up and that oftentimes can be a problem as well. So we talked a little bit about 2 joint muscles.

Scoliosis: Everybody fears that your child is going to get scoliosis after their hemispherectomy. Again, when I looked at PubMed 2 weeks ago I found no articles talking about this at all. I searched hemispherectomy spine, hemispherectomy scoliosis, hemispherectomy gait, nothing. There is nothing in literature about scoliosis from hemispherectomy. But in children who are more profoundly affected because they've got no head control or trunk control they do get scoliosis which is a big deal. The thing is that those children who can stand and can walk they actually never get scoliosis that means anything because they trunk control. If you have good trunk control what that means is that you basically won't get scoliosis because everything works and because almost all children with surgical hemiparesis will walk and have good trunk control eventually scoliosis in this population is an exceedingly rare problem. In fact, the study of Dr Lee at our hospital is actually getting a spine x-ray of every single post hemispherectomy kid every year for 5 years to see, I have 1 patient out of 200 kids that actually has a curvature.

*Audience: Is there a percent that you consider...?*

Yes. Absolutely. Anything less than 10% of so is not actually scoliosis. Anything which is posturally correctable, that is if you just tell the child to stand up straight and their scoliosis is better, that is postural control, that is post hemispherectomy weakness which you know is going to get better as they get stronger. It is the scoliosis that's 25, 45 degrees, that's a problem. It's the ones that don't get better no matter how you position the patient. If you get an x-ray on their back, on their side, it's still the same, that's the bad scoliosis.

*Audience: [---] So far she has positional scoliosis and can still straighten her, so are you talking about moving beyond that at some point into something that's not posturally correctable [---]*

So, the children who rely on their wheelchair for most of their mobility who don't stand or walk those are the ones that we are really worried about, does their scoliosis get worse? Now a lot of these children who have hemispherectomy who develop scoliosis weren't walking before they had the surgery anyway so this is a problem when you start talking about where is the data and literature on this? Well, the problem is that if you have children who have scoliosis after hemispherectomy the big question is how many of them had it before their surgery? How many of them were walking before their surgery who are not walking after their surgery? How many of these patients are still not walking after surgery? Because there isn't enough numbers to actually show that and nobody gets an x-ray of these kids before and after surgery, nobody gets an x-ray of these kids after surgery, there is no information and that's why we are doing this at our hospitals. We are trying to do this because there has to be some science and that's why there is no paper on this all. But if your child can stand and they can walk then I'll reassure you that this is not an issue. It is the children who can't stand and can't walk that really is an issue and that's where the research is going to go.

Usually if your child has bad scoliosis like this child here who has a [---] normally they also have hip problems, knee problems, foot problems. You won't see a child who has scoliosis and nothing else. The children who have bad scoliosis usually have such profound spasticity they are seeing you for multiple things. You are not going to see a child who just has scoliosis and nothing else. So if your child has got an orthopedic problem then they don't have scoliosis, if your child has an orthopedic problem that is significant like a hip problem they probably may have scoliosis and that's a problem.

So what are the take home points: Well, if your child hasn't been seen regularly by a pediatric orthopedist I would recommend that they are seen annually by a pediatric orthopedist. I would say that you should probably have them seen at least for 5 years after surgery just to be sure that if there is an incipient problem they are monitored and early intervention can be done with soft tissue surgery before they start having bony surgery.

The second thing is that if they have a relapse of their seizure activity that usually resets the whole game and that's a big problem so that is an issue.

Most problems can be treated without surgery like I said: Bracing and physical therapy works very, very effectively for the kids who are high function hemiparetic. Almost all children do walk and if you walk well with very minimal bracing, if they do walk with the bracing, maybe it's just an AFO.

Most of the problems, at least in these children, usually involve just the foot and the ankle.

Thank you very much, we'll take 3 questions and then we're way over time.

General guidelines [---] leg length discrepancies [---]

Most leg length discrepancies are not that significant, most of them are usually in the realm of about an inch or less and the reason why we do get the leg length discrepancy is usually because of some lack of neurological stimulation as your child grows. The way I explain it to my families is that if your child walks well, if it's a slightly short leg and they don't trip on their toes, what if you made their leg an inch longer, are they going to trip on their toes now? Probably. So some of that leg discrepancy is actually is quite function because that is all it needs for them to not drag that toe on the ground when they're tired. You make that leg an inch longer, now they are dragging their foot more.

The other thing is we talk about a leg length discrepancy, that's how you and I stand with our knees together and our legs locked straight. The reality is that we don't do that; we don't ever do that unless we are told to do that. All of us will cock one leg and do this, or will stand like this and that's the reason why we have these formats that are cushioned when we stand and walk because that's how our bodies adjust. So having a discrepancy that is meaningful has to be at least more than an inch for it to be a problem. If the discrepancy is less than an inch then you can easily accommodate that and it is not really a functional problem.

*Audience: What age would you offer to do that?*

Most discrepancies, you'd like to try to get them fixed before they're done growing because when you try to do a surgery to correct their leg length discrepancy it is easy to do it when they're still growing because you slow down the growth of the longer leg and you do it while it is still growing so the shorter leg catches up. If they're 15 years old there is no catching up, they're not going to be able to grow enough on one leg, you have to do it when you're about 12. So I would say 12 or 13.

*Audience: My daughter had her first surgery at 10 weeks old [---] by the time she was 1 year she had a 27% scoliosis curve, right now she has 65% scoliosis curve but she grew significant, last year she grew 7 inches so there was no standing prior to anything so if they don't want to do surgery what are my options to get her corrected because she is so [---]*

How old is she?

*Audience: She just turned 4, but she's the size of an 8 year old.*

So you're right, spine fusion surgery halts your growth and we don't recommend that in children who are less than 10 because there are some issues about how does a body try to grow when there are rods in the back, but there are rods which expands as a child grows and the rods that we use now is called a Magec rod, it is called a magnetically activated rod. These are temporary rods which you put into a spine and it is actually lengthened in the office 3 times a year with electric motor so the children who are less than 10 years old and have scoliosis of more than 50 degrees, they qualify for a magic rod placement.

*Audience: How old?*

Less than 10 years olds: Less than 10 with a curve of more than 50 degrees. So Magec – Magec rod. It is a magnetic growing rod for the spine. It is a wonderful surgery to do, it's 2 small incisions and a 1 night stay in the hospital and this surgery is actually done in such a way that as a child grows you don't have to take them back to surgery to make the rod longer, it is actually done in the office with a magnetic device that just activates the rod. Most hospitals don't encourage you to use it because the devices are \$17,000 per device, you need 2 of them, and because the hospitals can't recoup that cost, the surgeon's hospital may actually discourage the use of that device on the basis that it is not cost effective for the hospital.

*Audience: [---] traction for scoliosis, a halo thing, I don't know if [---] a candidate after...*

Yes. The traction treatment is good but it is pretty barbaric if you've ever seen it and I would say that for somebody who needs surgery who is very, very stiff that may be a good thing but most places will require giving traction for 6 weeks to 3 months before surgery.

*Audience: Will they regress back due to that right sided weakness?*

The purpose of traction is to try to get the spine more flexible so you can actually get it straight for the surgery. It is not really meant as a substitute for surgery but as an adjunct to surgery.

One last question.

*Audience: So, my son hyperextends his knee and he bends it when he [---] but if he is standing and it is locked and snaps back. He's 6, we have been trying to manage this with an AFO but we are not being successful at it so what [---]*

There is no surgery to make the knee tighter in the back. There are a lot of surgeries to make the knee more flexible in the back so the thing is you need to fix it before it gets so loose that it's not controllable. That's one of those more aggressive things that you need to be much more proactive in terms of limiting that from happening because as that stretches out as you get older you can't fix it, it's not fixable and your child will have to wear a longer brace.

*Audience: That's kind of what they said with the KAFO and he would still need a knee replacement by the time he was 8.*

That's absolutely right, I mean, I'd have to look at his AFO to see basically how they built it so a lot of times to fix that they will actually put a heel lift in the AFO, a big one so when he walks he actually crouches his knee.

Well, so gait analysis may help to see whether or not his quads are too strong or maybe he needs a selective muscle transfer where his quads will get weaker, so a rectus transfer may help him.

Thank you so much.

*For more information on lower extremity hemiparesis, go to [www.brainrecoveryproject.org](http://www.brainrecoveryproject.org)*