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Current Topics in Upper Limb Loss and Difference:  
Electronic Multi-Articulating Hands and Digits,  
Toe-to-Hand Transfers, and Hand Transplantations

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Presenter: Diane J. Atkins, OTR/L, FISPO  
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- [Fawn] Today's topic is Current Topics in Upper Limb Loss and Difference: Electronic Multi-Articulating Hands and Digits, Toe-to-Hand Transfers, and Hand Transplantations. Our presenter today is Diane Atkins. She is an internationally recognized occupational therapist specializing in upper limb amputee rehabilitation. She has worked with over 2000 children and adults with amputations and has lectured extensively throughout the U.S. and abroad in areas relating to the evaluation, treatment, training, and functional outcomes of individuals with unilateral and bilateral upper limb loss. She is an assistant professor in the Department of Rehabilitation Medicine at Baylor College of Medicine in Houston. She has been involved in several grants and research activities sponsored by the National Institute of Health and the Veteran's Administration and NASA. In advance of the Iraq and Afghanistan wars, she was asked by the United States Surgeon General to present several courses for the clinical rehabilitation teams at Walter Reed and Brooke Army Medical Centers regarding the management and care of soldiers who had sustained upper limb loss. She is the co-editor and author of two textbooks relating to the comprehensive management of children and adults with upper extremity amputation and has authored several peer-reviewed journal articles. She's a fellow in the International Society of Prosthetics and Orthotics and honorary member in the American Academy of Orthotics and Prosthetics. She is an amputee prosthetics consultant for Paradigm, the largest catastrophic case management company in the U.S. She has pursued a one of it's kind research project that is comparing the functional outcomes of individuals fit with state of the art electronic hands and those receiving unilateral and bilateral hand transplants from the United States and Europe. Diane was recently appointed to the prestigious advisory panel of the National Limb Loss Preservation Registry, excuse me. The registry supported by the National Institutes of Health and Department of Defense aims to establish the number of people living in the United States with limb loss in order to provide insight into their challenge and needs. It is designed to collect data that will improve the prevention, treatment, and rehabilitation efforts. Welcome Diane, we're so happy to

- [Diane] Thank you Fawn for that introduction, and welcome everyone. Today we're gonna be discussing Current Topics in Upper Limb Loss and Difference: Electronic Multi-Articulating Hands and Digits, Toe-to-Hand Transfers and Hand Transplantations. And as you see in the photos beneath the title, they're examples of each one of these. First, bilateral hand transplant example. The middle photo is an i-limb multi-articulating hand user. And the last is an example of a toe-to-hand transfer. We'll be talking about each one of these shortly. Before we begin Debbie LaTora had wanted me to share two text references that address the topic of amputee rehabilitation. I had the pleasure of co-editing and authoring a couple chapters in these books with a number of national and international experts in this field. Many of these individuals became my mentors and laid the foundation for where my passion and career has led. Some of the learning outcomes we hope to accomplish, you will be able to describe current advances and outcomes in electric multi-articulating hands and their functional abilities. You will be able to describe the history of hand transplantation, when they are considered, and what to expect. And you will be able to list some of the reasons the perception of disability is less in prosthetic users versus hand transplant recipients.

Okay, a little background of this study. To date there has never been a national or international effort designed to compare the dexterous abilities, functional outcomes and disability experience of individuals who have been fit with advanced electronic multi-articulating hands and digits, toe-to-hand transfers, and hand transplantations. First a quick review of some of the terms and acronyms that we'll be using today. First, autotransplantation, this is a transplant in the same body, as in a hand replant or a toe-to-hand transfer. This differs from an allotransplantation which is a transplant between two different individuals as in a hand transplantation. And this goes without saying, that one is a donor, someone who is deceased within the last 24 hours, and a recipient who is on-call, could be anywhere in the United States and is life flighted basically to the location of the donor recipient. What types of drugs are required in

order to prevent rejection from an allotransplantation? Immunosuppressive drugs and this is a very, very important reality of transplantation. Why? Because some of the side effects of taking immunosuppressive drugs are significant. Some of these include infections, metabolic disorders, disease, malignancies, renal insufficiency, diabetes, and in some cases avascular necrosis of bilateral hips treated with hip replacements. So as you can see there is a wide scope and realities of some side effects of these immunosuppressive drugs, but I will share that there are major advances that are being made in managing the complexities of immunosuppression.

Okay, a few more terms and acronyms. The autoimmune response to a transplanted hand or replanted hand is improbable. However, the alloimmune response to a transplanted hand is probable but complications are manageable. These are some of the side effects of immunosuppression that I was describing. VCA, VCA stands for vascularized composite allograft as in a transplant of a hand, hands, or face. This is also known as CTA which basically means the same thing, or composite tissue allograft. Composite referring to skin, muscle, bone, and nerve tissue. Additionally tendons and arteries as well. So as you can see, this is a highly complex procedure. Okay, a little bit about the historical review of hand transplantations. The first transplantation was performed in Lyon, France in September, 1998. The operation was technically successful, however the patient proved to be noncompliant with immunosuppression and the hand therapy that was required. He left the care of the Lyon group and required an amputation in 2001.

Okay, what are some of the lessons that we've learned? And they're just one of many to come. The psychological screen that is done prior to a hand transplantation is critically important. Patient compliance with immunosuppression is essential. Initially up to 50 pills a day were required, thankfully today there are quite a few less, but again, adherence to this protocol of the immunosuppression is critically important. Patient compliance with therapy, and this is very significant, therapy for up to two years

following a hand transplant. And therapy that could include six hours a day, seven days a week. And I can say in the centers that I've visited, specifically the program in Innsbruck, Austria, that adheres to this guideline to the letter, their outcomes are outstanding of their patients. But again, as you might suspect, this is a huge commitment of time and effort on behalf of the individuals who have agreed to a hand transplantation. The survival of an allograft and the psychological ramifications surrounding transplantation of a viable, sensate, and functional part differ greatly from a solid organ transplant. A solid organ transplant is one that many of us are already familiar with, the heart, lungs, kidney, which indeed are complex and obviously very, require the skilled surgeon, but when we're talking about VCA, these procedures are much more complex and much longer. And require a much larger team of surgeons.

Okay, since 2000 and when this slide was made, 110 transplantations had been performed. Today there are close to 200 on many, many patients worldwide that include unilateral and bilateral. The prevailing feeling today is that bilateral is more appropriate because of the lifelong immunosuppression. We would not routinely immunosuppress someone who is requesting just a unilateral transplant for obvious reasons. There sound arm and hand can do, as we as OTs know, the majority of what we need to do in our world. So, really this procedure is considered more often for bilaterals. So the primary transplant teams abroad in my experience are Austria, France, and Turkey. And believe it or not, in Turkey, they're even performing lower limb transplants. The United States teams include several centers of excellence. The three with which I am most familiar and have performed at least 10 hand transplants to my knowledge are the University of Kentucky at Louisville, Johns Hopkins, and the University of Pennsylvania. The surgical teams at each of these centers have trained for years in this procedure. And they represent specialties of primarily plastic, microvascular surgery, and orthopedics. The most current state of the art facts shared at the last American Society of Surgery for the Hand, and many of these are still current today. As I was just stating, the bilateral transradial amputee is considered to be the

most appropriate transplant candidate for reasons that I just described. Prosthesis must be trialed for at least six months before and individual is considered for a transplant. And I highly agree with this recommendation.

A comprehensive team approach to screen a candidate is required, which includes rehabilitation medicine, OT, and social work among the many other surgical specialties. Additionally, three psychiatric specialties that represent transplant, PTSD, and depression make certain that the candidate is acceptable. At least 10 cadaver rehearsals are required for anyone to be on the transplant team. The procedure for bilateral upper limb patients, averages 18 hours with 32 surgeons per donor/recipient procedure. What this basically means is 16 surgeons are assigned to the donor, 16 to the recipient. Eight surgeons are assigned to each arm. These specialists represent expertise in bones, tendons, arteries, nerves, veins, and skin. Immunosuppression is one of the most challenging aspects of the transplantation experience. Gerald Brandacher from Johns Hopkins is currently working on a new protocol that is bone marrow based, utilizing stem cells which could result in a single agent to deal with immunosuppression, which truly would be terrific. A committed compliance from the patient to the transplant program and protocol is critical. And I can't stress this enough.

Okay, there is a debate however, that exists as to if these procedures are really appropriate. Lifelong immunosuppression is a huge consideration. So we're looking at quality of life versus quantity of life. And the debate revolves around because the hand transplantation procedure is considered life enhancing as opposed to life saving, ethical issues are balancing the risks and benefits and remain a foremost consideration. The goal of CTA therefore is not to save lives but rather to restore function and improve quality of life. So this is a very, very important concept. And one that continues to revolve around the appropriateness of this and for the individual who is contemplating this, they must be completely on board to understand this isn't

necessarily going to save your life or extend your life, but enhance your life. And is this a decision that you really want to make? Now, if any of you live in the Philadelphia area, you may be familiar, and actually anywhere in the United States for that matter, because this young man actually received quite a bit of exposure and notoriety for good reason. The surgeon in this photograph is Dr. Scott Levin who I have the utmost respect for. He is the Chairman of Hand Surgery and VCA at the University of Pennsylvania Medical Center. Zion is the youngest bilateral hand transplant patient in the world. He contracted sepsis at age four, he lost both arms below the elbow, and both legs below the knees. He was already immunosuppressed with a kidney transplant. So when not adapting to bilateral prosthesis, and meeting the psychological criteria, the decision was made by his mother and Zion to have a hand transplantation. Zion is one of the most successful bilateral transplants and the world's youngest. And I wanna reinforce that he was already immunosuppressed with a kidney transplant.

So that's why the decision was made for such a small child that this procedure actually could be considered. And actually in his case it was extremely successful. The lower left hand photograph is special, because Zion actually threw out the first pitch at one of the Phillies baseball games last year. So he is quite a celebrity in the area. Okay, moving right along to my study and research that I've been involved in doing. And before you read the narrative on this slide, I just want to give a quick background about Neil Jones. Dr. Jones is an internationally known surgeon and one of the most experienced in toe-to-hand transfers. He's the Chairman of the Department of Hand Surgery at UC Irvine. Four years ago he approached the CEO at Touch Bionics, Touch Bionics is the manufacturer of the i-limb, which is the first multi-articulating hand that became available on the market. And Dr. Jones was aware of the controversies surrounding hand transplants. He also was becoming more aware of multi-articulating hands and he approached the CEO of Touch Bionics. And he asked would you be interested in a comparative study looking at the outcomes of those that have been recipients of hand transplantations?

Let's look at some of your patients that have been fit with multi-articulating hands. And he said, I'd also like to include some of my patients with toe-to-hand transfers. So the CEO approached me, I was a consultant at the time, and because of my background in academic medicine and research I enthusiastically replied, "Yes." So, the goal of our study was to define a functional baseline index, or an FBI score, or standard that defined a measure of functionality of individuals who were fit with multi-articulating hands and digits, those who had had toe-to-hand transfers, and hand transplantations. The study was preliminary and clearly will require additional subjects. But it did set the state for future investigation and research into the dramatic advances that have occurred in the fields of reconstructive hand surgery and the emerging technological advances in electric prosthetic hands.

Okay, the subject population. Now, granted this population is small, but when you consider what I was studying it's really quite large. Five individuals were included with unilateral and bilateral hand transplants from Innsbruck, Austria, and different parts of the United States. There were 14 unilateral and bilateral users of electric multi-articulating hands and digits from the United States. And there were six individuals with unilateral and bilateral toe-to-hand transfers. These individuals were patients of Dr. Jones. My methodology included four validated and standardized tests. These included the box and blocks, many of you are familiar with this. Which measures manual dexterity that basically is represented when someone repeatedly moves one inch blocks from one side of a box to another in sixty seconds. The nine hole peg is a timed measure of fine dexterity that involves placing and removing nine hole pegs in a pegboard. So we're looking at more of a fine motor function versus more of a gross motor function in these two tests. These two are objective measurements. The DASH, many of you are sure I'm familiar with, this is a subject measurement. It is a 30 item, self-report questionnaire designed to help describe the disability experience by people with upper limb disorders. And last, this is an objective measurement, this one is used



more and more in prosthetic evaluation. It is the Southhampton Hand Assessment Procedure, the SHAP, it is a timed test with eight abstract objects and 14 activities of daily living designed to study eight different prehensile patterns of grasp. It's very important in this research for me to stress that an independent and experienced occupational therapist performed all of these assessments of the study subjects. It was not myself, I did not want to enter any bias into these results, or hint of bias. But I was very fortunate to have a very skilled and experienced occupational therapist from NYU. And we were a team, we traveled to Austria together and several cities throughout the United States to conduct this research study. We also wanted to include sensation. Because obviously sensation is critically important, something all of us take for granted. And it is the true benefit of a transplanted hand, as well as a toe-to-hand transfer. Sensation really is the holy grail right now of prosthetic research as we try to reproduce different types of sensory feedback in prosthesis and study how it can be reproduced. But to be honest, we're not there. It's going to take a lot more time and research, but there's a great deal of time being spent on this. But for those who have toe-to-hand transfers and hand transplants this clearly is something they are pleased with. It makes a huge difference in their function and yes, it progresses over time, but I have seen several of these transplanted patients be able to have very discreet two point discrimination which is really quite remarkable.

Okay, now we're gonna take a look at a couple of these subjects as they are demonstrating some of the assessments in my study. The first video is a gentleman who was fitted with a unilateral, he is a unilateral transradial amputee and he will be demonstrating an electric wrist rotator. He will be, okay, I want you to look very carefully at this. He has an electric wrist rotator and an i-limb hand. What he is demonstrating is excellent, excellent tip pinch and fine motor dexterity. Okay, let's take a look at the next video. This is one of the gentlemen from the Innsbruck program. He is a unilateral hand transplant. And he is, he is showing as you can see a bit of shoulder substitution and there's a little bit more engagement of the entire arm. Okay,

the next example you're going to see, okay, let me advance that. The next example is going to be a toe-to-hand transfer subject. And this is a young girl, Shiloh, who is actually one of Dr. Jones' patients. She was born with a congenital anomaly of her hand. And I want you to look closely at her second digit. This is a transplanted toe from her foot. Yes, it's actually quite cool when you see the dexterity and range of motion, right. The pronation and the supposition that she has at her wrist and forearm, of course that's a function of not the procedure, but the unique abilities of her hand. Shiloh has no functional limitations. She has no issues with her feet. And she has had a very, very quick recovery.

Let's go to the next slide. All righty, now let's look at some of the results, specifically of the bilateral subjects in my study. 'Cause this is the group that I really want to focus on. There were three, it includes three bilateral amputees fit with electric multi-articulating hands. Four bilateral amputees with hand transplants, two from the United States and two from Austria. And one bilateral patient, and he is very unique, he had six toes transferred to two palms that lost all the digits in a tragic burn injury. So three toes were transplanted from both feet to each hand. You'll see more of him in a second. He is the only patient in the world, the only individual in this world where this procedure was performed by Dr. Jones.

Okay, let's take a look at the subjective results in response to the DASH. And as you know in the DASH, the lower the score, the lesser the perception of disability. So take a look at this. The individual with the bilateral toe-to-hand transfer had the lowest perception of disability. He is totally independent. He runs, he plays basketball et cetera. The bilateral transplants do perceive themselves a bit higher in their level of disability, not a great deal of difference, but indeed there is some. The bilateral prosthetic users are in between. Okay, let's look at the objective measurement, the SHAP, again this is the timed test with abstract objects, activities of daily living, and studies eight different prehensile patterns of grasp. Take a look at this. The higher the

score, the more functional they are. All these groups have very high scores and there really is very little difference between them. Again, the bilateral toe-to-hand has the highest, bilateral prosthetic users are close, maybe a little bit less than the bilateral transplant. To be honest when I embarked upon this study, I really thought it would be a slam dunk so to speak, in favor of bilateral prosthetic users, simply because my background in training individuals with bilateral prosthesis was actually pretty remarkable. And they become very independent. I had no idea, partly out of my own ignorance, how well transplanted patients could perform. So this was quite remarkable.

Okay, let's take a look at one of them, one of these bilaterals. Jason, in March of 2008, he sustained 7200 volts of electrocution, of electricity. He is and was, totally independent with body powered prostheses before he was fit with electric hands. He is one of the first bilateral transradial amputees to ever wear i-limb hands. And at the time of this slide and my study, he had been recently fit with the second generation of i-limb revolution hands. Okay, let's take a look now at the video of him which is really quite remarkable. You're going to see him perform, well you're seeing it right now. Making some scrambled eggs, showing very smooth pronation and supination, grasp and release opening that milk jug. Having the strength to pick up that gallon of milk, pouring it. You can see the ease with which he's executing this. Grasping this mixer, I forget what the technical name for this is, but as you can see he is really quite adept. Okay, here we go to the next slide. Okay, you're going to hear Jason now as we run the first video in this slide of him opening a coke can. I'm gonna be quiet so you can hear him.

- The lever to pop it open. So when you get down right here, it gets stuck on your fingernail. See what I'm talking about, like right there. And it doesn't allow you to get underneath it. So you gotta hold it just a little bit higher. And you gotta use your thumb to push down.

- [Diane] Okay, that is really quite remarkable. Even for us to perform with two good hands. You could see, you can start running the other video now if you don't mind. You could see how easily he held the can with good grasp and the fine motor abilities. Now you're gonna see again a little bit more of this scrambled egg procedure. Take a look at how he's managing that egg shell, very, very carefully. Something that's, so he's clearly controlling the amount of grasp that his hand is able to, to perform here. And I can say based upon my experience with these folks, they visually yes are attending to this task, but there is also almost a sixth sense of a proprioceptive and kinesthetic feeling that they feel through their electric hands that enables them to do something like this so well. So, needless to say, Jason is really quite remarkable and truly one of the best users of electric multi-articulating hands.

Okay, let's take a look now at a bilateral hand transplant. Sheila contracted bacterial meningitis in July of '03. She had bilateral transradial and bilateral transtibial amputations performed. She was initially fit with bilateral body powered prostheses and became independent and returned to work. She had tried bilateral myoelectrical prostheses and just didn't like them, they were just too heavy. In December of '09, she had heard about hand transplants. She approached Dr. Andrew Lee at the University of Pittsburgh, who since moved to Johns Hopkins. And in October of 2010 she sustained, or was under a 12 hour hand transplant surgery procedure. She today is totally independent. She drives, and has returned to work as an administrative assistant.

Okay, let's take a look at the first slide which will demonstrate her very good ability. as you will see, to write. Take a look at her forearms though. You do see clearly where the arms were attached, but take a look at her writing ability. It really is quite good. And you know, aside from yes, the attachment locations on the forearm, the cosmetic results of this procedure is really quite remarkable. Okay, let's take a look at her in her home. So I had the unique experience of spending a day with Sheila in her apartment. As I shared, she is totally independent. And she had made a meal so I wanted to see

how she did with washing and loading dishes in her dishwasher. And as you will see, she is really quite adept at this. Again, take a look, you can see where the arms were attached. But again, actually she is really quite good at doing this task. The next video is perhaps even more remarkable. One of Sheila's interests, she was quite an artist. And still is an artist with paint, but she also enjoyed macrame in the past. This activity is really remarkable to me because for her to be able to finger weave, so to speak, and use the fine motor coordination that's required in this task was really astounding to me. This for her just was quite commonplace. It was something that she wanted to do and learned to do quite well in therapy.

One other point I just wanna make about Sheila right now, which actually is quite unfortunate. She has, I just discovered several months ago, that she has developed stage four kidney disease as a result of long term immunosuppression. This is a very unfortunate side effects, it was not anticipated and the teams at Johns Hopkins I believe right now are doing their best to manage this, but again, these things happen and it is a very unfortunate side effect. Okay, let's talk about Marius. Marius is the young man who in May of '08 sustained severe burn injuries while caught in his families burning home in Romania. He lost all fingers from both hands. Severe facial and lower limb burns. He was treated at LA Shriners, the Los Angeles Shriners Hospital by Neil Jones who performed a six toe-to-hand transfer to both of his palms. Today he walks, runs, plays football, basketball, and he's totally independent. And we're just gonna run a very short clip now of him performing one of the SHAP activities. You can see how, now these are toes from his feet, okay. Three from one foot, three from another. And this is one of the tasks of the SHAP test. Basically what he's being asked to do is slice through the ball of clay. At the conclusion then he ends the task after putting the knife down, because it is a timed test.

Okay, let's go to a couple other quickies of him demonstrating again his fine motor abilities. And we can run the first one in putting on his socks. So as you recall, the

majority of his body was burned. You can see the effects of that on his legs. But take a look also at his feet. Yeah, three toes are gone. The great toe, second and third. Fourth and fifth toes have migrated over a bit, but his balance is fine. And as I say, when I saw him walk into the room, he walked totally fine. He runs cross country so there were not any issues with his ability to be just as normal as you and me. And I think this was really surprising, even to the surgeon. Although admittedly, Dr. Jones certainly wouldn't have performed this procedure if he did not clearly describe, yes, there may be some issues in his ambulation abilities. But there were not.

Okay, let's take a look at the next one real quick. This is another activity of the SHAP assessment. And again, it's showing Marius' ability with that wide grasp and also his ability to turn the lid of the jar. Okay, let's look now at some of the key differences of each subject group as it relates to the rehabilitation experience. Just to review a little, okay. The time from procedure to function varies greatly. In prosthetic users we can actually look at the rehab time, three to six months. Hand transplantations, 18 months to two years. In large part due because the slow growth of the peripheral nerves that are innervating the muscles. Toe to hand, two to three months. The amount of therapy, prosthetic users, one to two hours a day, three times a week, three to five weeks. Flip side of that, hand transplants up to seven days a week, five to six hours a day, for sometimes dependent upon how proximal the transplant, one to three years. Toe-to-hand, minimal if any. Medications basically none or some maybe to manage pain and other issues. Hand transplants it was up to 50, it's now less, but clearly a very important consideration. Minimal in toe-to-hand. Potential complications, little in the prosthetic users. Hand transplants, yes. Sensation, no, prosthetic users. Yes in hand transplants and toe-to-hand. And this is the real bonus obviously of these two procedures. Appearance, it's all in the eyes of the beholder, but in my opinion they're all actually quite good.

Okay, let's look closely at the results. Early results reveal that the outcomes of hand transplants, two years or more post-procedure demonstrate similar outcomes of prosthetic users of advanced hand technology as it relates to ADL, fine motor, and manual dexterity. What is interesting, however, requires further investigation is that subjects who utilize electric multi-articulating hands and digits perceived themselves as less disabled when compared to hand transplants. So, let's take a look. These are my thoughts as to why there are some possible reasons the perception of disability is less in prosthetic users versus hand transplants. Okay, one of them could very well be, the time from onset to upper limb loss to being fit and functional with an upper limb prosthesis is considerably less than the duration of time required for hand transplantation. So we're talking again about three to six months in someone who has been fitted with multi-articulating hands or body powered prostheses versus 18 months to two years. Prosthetic users, yes, become independent sooner and therefore see themselves as less disabled.

Okay, number two, this was another thought of mine. The fine motor abilities of those who have been fit with advanced multi-articulating limbs is one area of dexterity that appears to be superior to those with hand transplants. These are just, and we're gonna talk about intrinsic return in a moment, but just take a look at these photos. You see the i-limb hand holding a die, you see a hand transplanted hand who actually was not on the receiving end of hand therapy as we suggest, somewhat of a claw fitting hand, doesn't have good intrinsic fine motor dexterity. Still functional, yes, but not with the fine motor abilities of what a multi-articulating hand could include. And then we have two examples of, this is part of the SHAP, and that is just grasping the zipper, the zipper piece. And basically zipping and unzipping with the i-limb hand and then a transplanted hand. The zipper tab, that was the word I was using, looking for. Tip pinch is one of the last fine motor abilities that is possible with hand transplants, and even then it is not always achieved. So again, here are some of the prehensile patterns possible with multi-articulating hands. Yes, believe it or not, this is someone with

multi-articulating hands and a custom high-definition silicone glove. It's actually difficult to tell at first glance which is the sound hand and which is the hand that has been fit with a multi-articulating hand. Recovery of the intrinsic muscles of a transplanted hand is observed on average not until nine to 15 months following transplantation. Different degrees of intrinsic return are based upon the skills and experience of the transplant team. And the frequency and duration of occupational therapy.

And again, I cannot stress this enough, the commitment of the individual who is receiving a hand really needs to give at least 12 to 18 months of their life to actually relocate at the center of excellence where the transplant was performed. These slides show some of the less than optimal outcomes of some of the transplanted hands. Again, these hands are functional but not to the extent of some of the other hands that I've seen that were performed at some of the major centers, have to say it. Innsbruck being one of the finest. Penn, Hopkins, and Louisville are also very much in sync with what clearly is required for these individuals. Okay, and let's look at my third sort of hypothesis regarding some of the possible reasons why the perception of disability is less in prosthetic users versus hand transplants. Once the amputation is performed and an upper limb prosthetic fitting and training has been accomplished in an upper limb amputee, that individual has essentially finished with their amputation/rehabilitation program. Ongoing medical treatment, frequent followup and numerous immunosuppressant drugs however are required in the hand transplant patient for the remainder of their lives. They continue to see themselves as a patient versus an independent back to work society individuals. This is, I'm painting somewhat of a broad brush here. The only reason that I express that they see themselves as a patient is they do need to return on a frequent basis to the centers where they were treated because the centers need to be very cognizant and very much on top of their blood levels, what is going on in their body, and they often do need to return because



of infections and a variety of other side effects that sometimes do appear and indeed do need to be managed.

Okay, what are some of my ideas, hopes, dreams and future goals for the direction of this study? Well, I would very much like to add additional prosthetic users and hand transplant subjects to grow this study, to really see if the results that I've observed thus far are consistent. I want to be able to continue to build bridges of understanding between rehabilitation, surgery, and third party payers. This is perhaps one of the most exciting offshoots, side effects, benefits of what I've been able as a therapist to experience. I have been invited to speak at a number of national and international reconstructive, plastic surgery, and orthopedic meetings about this study. And it's been the first time that to my knowledge these surgeons have been interested in what's going on in the world of amputee rehabilitation. For me that's very exciting. I've been able to introduce them to live patients and also my videos of what amputees are able to achieve. And it has been extraordinarily surprising to them. They had no idea. Third party payers really need to see and understand this as well. And this is an ongoing goal of mine, because clearly these procedures are expensive, we need to find coverage, and we need to inform and educate third party payers about them. I wouldn't be able to define success in a way that's universally understood. Many times surgeons will say, "Oh the outcome "of this particular procedure, of this hand transplant "was a success." And then they move on and continue their dialogue and talk, but we as OTs, we wanna know what does success really mean. A good take of a transplanted limb, well that's one thing and maybe to a surgeon, yes that means a lot. But I want them to really be able to understand what is success really mean. We need them and their therapists to describe that is more functionally based. Because we do that as therapists when we describe success in our prosthetic users.

And last and perhaps most important, I want to enable the individual who has lost one or both hands to be able to make an informed decision about what options are out

there and have as much information as they can from those who have been involved in these procedures. And as much evidence-based outcomes that can be demonstrated as to what can be expected. So, in conclusion, this is just the start of hopefully more to follow. But I hope you agree this is really quite exciting with more to follow. I appreciate your interest and attention, and I am happy to answer any of your questions.

- [Fawn] Thank you so much Diane for a great talk and some amazing videos. The first question

- [Diane] You bet.

- [Fawn] That came in is what is the cost of an i-limb hand?

- [Diane] Okay, very, very good question. The i-limb hand dependent upon who is fabricating the hand can vary anywhere from 90 to 110,000 and believe it or not there can be even plus or minus five or 10 on either side of that equation. Yes, they're very expensive. It is extremely important for that hand to be, that entire prosthesis to be made by someone who is skilled in that. And dependent upon who the insurance carrier is, and who is the provider, there may be a contract that exists where a discount can be given. But I've not really seen any of these hands less than \$90,000. So they're very expensive.

- [Fawn] Okay, another question coming in is how close is the technology to giving a signal of temperature.

- [Diane] Ah, very interesting. There's active research now. I wish I could look into my crystal ball and tell you where we are with respect to temperature. I couldn't tell you when that's going to happen. Vibration is being addressed, is felt within the limb right now. There actually some procedures that are invasive and connecting to the sensory

nerves of the arm to give some sense of feedback. And this is an arena that is very exciting. It's still obviously in the research phases, but I do believe we're actually advancing much more quickly than we thought we, where we would be five years from now. So, I think we're gonna be seeing something quite dramatic within the next three to five. If not sooner.

- [Fawn] Okay, another question is what is the cost of hand transplant surgery and does insurance cover this?

- [Diane] Okay, very good question. The hand transplant procedure, again can vary from location to location but it's essentially the same. \$100,000 or so for that procedure to be done as you can imagine with all the surgeons and the time that's involved. The unique reality however is that is a one time procedure. When we look at the, and compare this cost to the actuarial costs of replacement and maintenance of a prosthesis, we're looking at replacing a prosthesis, dependent upon use about every seven years. So you have the expenditure of 100 to \$120,000 happening over the life of someone, compared to \$100,000 plus procedure at the outset of a hand transplant. So, the hand transplant is actually less relatively speaking, but the insurance issue is a whole nother factor right now. The procedures that have been done, have been done at major university centers of excellence. And these universities have basically taken the brunt and stepped to the plate, I must admit to cover the costs. They see that, they're research based institutions, they see that this is really something that they need to support. But they are to the point now where they really need to look to other sources of payment. So insurance is something we are looking at collectively to raise level of awareness so that they might start to cover these procedures.

- [Fawn] Going along on that same idea. What is the cost of toe-to-hand transplant?

- [Diane] Ah, good question. You know, you know I don't really know. That's a good question. The majority are done and have been done by Neil Jones and those within the Shriners system. And as you know within the Shriners system, the beauty is, there is no cost to the family. So I've never actually really been privy to see what the cost of that procedure is. I must admit, in all of my years of working in rehabilitation, this was a procedure I had no exposure to. And I was amazed at the abilities of the individuals, children and adults, that I've seen that had this procedure. And the residents and fellows that studied with Dr. Jones, they are doing it in different locations throughout the United States. But I have to say they're few and far between. I really do believe this procedure needs to be considered more often, because I think it's really worthwhile.

- [Fawn] Okay, great. Another question, does one need to experience wearing both a body powered as well as a myoelectric prosthesis before being considered for a hand transplant?

- [Diane] Okay, good question. The answer is in my view yes, ideally. I'm not certain if that's followed in every center. They at least need to, as I shared before, experience a six month trial of a prosthesis. What are some of the reasons that these are rejected? Well, they could be many. Psychological is probably the most, common reason why someone just does not adjust to wearing a body powered or an electric hand. There could have been difficulties with fit, with comfort and a variety of other things, but that individual really needs to experience what it's like and again be fully informed as to what a hand transplant procedure is going to entail. As we've covered many times in this talk. So, any other questions?

- [Fawn] Last question coming here, yeah there's one more. Are there any limitations to the type of physical activity that a person with a hand transplant can do?

- [Diane] Great question. Well, again I was really, really surprised meeting one of the young ladies in her early 20's who had a bilateral hand transplant from the University of Pennsylvania, Dr. Scott Levin. This young lady, believe it or not, is an extreme sports competitor. She is able to perform pullups, pushups, she climbs rock walls. She does traveling rings. She actually competes competitively with able bodied individuals. When I saw some footage of this, it was extraordinary. Again, I couldn't believe it, but she indeed was one of the best outcomes of this very unique bilateral transplant experience. So, I wanna thank you very much. I don't know, Fawn, if you have any other concluding remarks but thank you for your attention today. And my email is here, I am more than happy to follow up with any of you if you have any questions, after. Thank you.

- [Fawn] Great, Diane. Thank you so much for a great talk. Again, those videos were just terrific to watch. I hope everyone enjoyed that. I also hope that if you were not able to view any of the courses this week during our virtual conference that you get a chance to check them out on our library. They'll be available soon as videos. I hope everyone has a great rest of the day. You join us again on continued and occupationaltherapy.com. Thank you.