

## 2005 ACPOC Annual Meeting Abstracts

### THE SEARCH FOR THE PERFECT MATERIALS

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Facilitated by staff of Rehabilitation Institute of Chicago, Children's Healthcare of Atlanta,  
Center for Limb Differences of Grand Rapids*

Interactive workshop facilitated by 3 Limb Deficiency Center PT's and OT's. We will explore, discuss, generate, and compile child and family friendly educational materials used for general limb deficiency and diagnostic-specific PT/OT education.

Specific topics will include 1. Skin /Scar/ Edema Management 2. Diagnostic specific exercise programs including conditioning and fitness components.

Participants will be asked to bring any relevant programs, protocols, handouts, videos, books, products (or lists of) that are used frequently and successfully. We will discuss systems for providing these resources (loan, purchase, list, library) as well as timing and best ways to present.

If this general workshop proves helpful, future topics can expand to address other topics.

### ADULT OUTCOMES IN FIBULAR DEFICIENCY FOLLOWING AMPUTATION OR LENGTHENING

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Fibular deficiency (FD) is the most common congenital deficiency of the long bones. Amputations or limb lengthening during childhood are accepted treatments to manage the small, unstable foot and the limb length discrepancy that results. The purpose of this study was to compare adult outcomes for these two treatments.

**Methods:** Records and radiographs of all patients now over 21 years with FD at 5 centers were reviewed. The diagnosis was confirmed in 235 patients. From this, 97 met inclusion criteria for our follow-up study of unilateral FD treated by amputation or lengthening. 57 patients (32 with amputations and 25 with lengthenings) were located for follow-up. The following questionnaires were administered by phone or in person: general demographic information, Beck Depression Inventory-II (BDI-II), Quality of Life Questionnaire (QLQ), and SF-36 (a general health questionnaire). A control group of 28 adults was used for comparisons with the BDI-II and QLQ.

**Results:** There were 37 males and 20 females. The average age was 32.3 years. Lengthening resulted in more surgeries and days in hospital ( $p < 0.0001$ ). Comparing treatment groups, there were no differences in educational achievement, employment, income level, public assistance or disability. ( $p = 0.14-0.57$ ) There were no statistical differences in reported pain or use of pain medicine. ( $p = 0.45-0.94$ ) There were no differences in participation in sports or reported activity restriction. ( $p = 0.2$  and  $0.16$ ) There were no differences reported in comfort wearing shorts, appearance or satisfaction with treatment. ( $p = 0.2-0.92$ ) No patient with FD reported indicators of depression. The only significant difference on the QLQ between treatment groups was the Job Satisfiers content scale with the amputees scoring better than the lengthening patients. ( $p = 0.028$ ) Both groups of FD patients scored significantly better than our controls in 5 other QLQ scales. ( $p < 0.0001$  to  $0.007$ ) though, all groups, controls and FD, had means ranging from slightly below to slightly above average. The results from the SF-36 did not indicate any health differences between the amputation or lengthening treatment groups. ( $p = 0.22-0.92$ )

**Discussion:** Because of the retrospective nature of this study and the clinical variability of fibular deficiency, it is impossible to have completely matched groups for comparisons between amputation and lengthening treatment. As expected, lengthening patients had more surgical intervention than those with amputations. Because many advances in medical care have occurred since these patients were treated, the number of hospital days and perhaps the number of surgeries would be far less for both groups if they were treated today. Despite higher initial costs due to greater medical/surgical intervention, other authors have reported that, if the lifetime costs of

prostheses are included, lengthening is less expensive than amputation. While it was our initial impression that those patients with amputation had a better childhood because of less time in treatment, this study was able to show better outcome in only one of 17 quality of life parameters. Both groups of FD patients are functioning at high levels with average to above average quality of life compared to the adult population.

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### **COMPARISON OF TWO DYNAMIC FOOT ORTHOSES ON CHILDREN WITH DELAYED GROSS LOCOMOTOR SKILLS**

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*\*Rainbows United Inc; \*\*Wichita State University, Wichita, Kansas*

**Purpose:** To compare the effects of two types of minimum control dynamic foot orthoses, pattibob (PB) and pattibobplus (PB+)(DAFO™ PattiBob, Cascade DAFO, Inc), on children with delayed gross motor skills.

**Methods:** The PB is (a) a shoe insert consisting of a thin layer of plastic on the bottom of dense foam (aloplast-like material) contoured and shaped to fit the plantar surface of the foot, (b) is constructed of low density polyethylene (LDPE), (c) is flexible at the toe, semi-flexible at the arch, and rigid around the heel, and (d) features include an arch support, a metatarsal head depression, heel cup, and toe rise for toes two through five. The PB+ is similar to the PB except for the following; (a) the PB+ semi-flexible plastic extends upward for ½ inch under the lateral and medial malleolus thus supporting all three cuneiform bones, the cuboid, navicular, and base of the metatarsals and (b) the lateral and medial flexible plastic tapers to and stops at the head of the metatarsals (i.e., support ends at the metatarsophalangeal joints). From a population of 53 motor delayed children, two groups with 12 children each selected and matched in diagnosis (motor delayed with or without Down syndrome or autism) and chronological age (PB = 39.9±7.3 mo; PB+ = 42.4±9.0 mo), as well as motor locomotion capacities (z-scores: PB = -1.72±.5; PB+ = -1.67±.61 and motor age equivalent: PB=22.8±6.2 mo; PB+ = 25.1±6.7 mo) as determined by the Peabody Developmental Motor Scales Test-2 (PDMS-2). Each group was fit with either the PB or PB+, allowed 7 days to wear the inserts, then re-tested using the PDMS-2.

**Results:** Significant ( $p < .05$ ) motor improvements were seen while wearing the inserts for both groups in raw scores (PB: 102.6±18.4 vs 105.8±18.5; PB+:109.6±18.1 vs 113.2±18.6). However, significant improvements in age equivalent scores were seen for the PB+ (25.1±6.7 mo vs 26.7±6.9 mo) but not the PB (22.7±6.2 mo vs 23.7±6.4 mo).

**Conclusion:** Results of this study and those of Pitetti & Wondra (2003) suggest that both the PB and PB+ could play a significant role in improving the gross locomotor skills of children with motor delays. Although results suggest that the PB+ resulted in greater improvements in motor capacity, the limited number of participants in this study prevents definitive conclusions.

### **TEMPERATURE DIFFERENCES IN A VENTILATED AND NON-VENTILATED TRANSTIBIAL SOCKET**

*Steven Thomsen, CP; James Athearn, CO; George Gorton III; Kelly Anne McKeown, MS; David Drvaric, MD*  
*Shriners Hospital for Children, Springfield, MA*

**Purpose:** To determine intra-socket temperatures and to measure the effect of putting a ventilating window into the wall of an amputee's socket.

**Material/Methods:** Ten subjects between the ages of 12 and 21 wearing a transtibial prosthesis walked on a treadmill for two test sessions. During each test, the subjects wore one of two styles of sockets: a standard PTB-SC design with a perforated Pelite® liner, or the same socket and liner with a ventilating mesh-covered window placed in the side of the socket wall. Both sockets were tested in the same manner during the same time of day on different days. Intra-socket temperatures were collected during both treadmill sessions.

**Results:** The results of this study showed the temperatures inside the socket of a transtibial level amputee. The results also showed the temperatures inside the sockets of the same subjects wearing a socket with a ventilating window.

**Conclusions:** There is enough heat loss with the ventilating window to warrant further study in developing materials and methods to increase patient comfort by decreasing intra-socket temperatures.

**Clinical relevance:** Since it was found that a ventilating mesh window in the side of a socket created a cooler socket, amputees of all levels will benefit from this research through the development of heat-wicking materials and fabrication techniques incorporating a ventilating window in their sockets.

### **THE EFFECT OF GEL PADDING ON PRESSURE DISTRIBUTION IN ANKLE FOOT ORTHOSES**

*Patricia Lawrence, MD; Linda Fieback, MA, PT; Andrew Cinque, CPO; Xiaofang Wei, MD; Angela D'Alessandro, MD; John Rossi, PTA; Heather Onorato, ATC; Steven W Lichtman, EdD  
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**Background:** Ankle foot orthoses (AFOs) are widely utilized to aid in ambulation and positioning of individuals with neurological impairments. During custom construction, an orthotist will attempt to strike a balance between form, function and comfort. Orthotists have several materials available to them in the construction process and can use a variety of inlay pads in an attempt to fabricate the orthosis with an optimal pressure distribution and fit for each individual patient.

**Objective:** To investigate the effect of gel padding on pressure distribution in ankle foot orthoses.

**Design:** A prospective, experimental, randomized, single factor repeated measures design will be utilized.

**Participants:** An incidental sample of 15 ambulatory and non-ambulatory neuromuscular impaired children and adults will be recruited for participation. All subjects will be chosen from individuals that receive care as inpatients or outpatients at Blythedale Children's Hospital. Patients at Blythedale Children's Hospital already clinically scheduled to receive an AFO will have a second set of orthoses made and screened for entry into the study utilizing the following inclusion criteria: diagnosis of a neuromuscular disorder, age over 6, flexible or fixed foot/ankle deformity. Exclusion criteria includes open wounds to the foot or ankle, progressive neuromuscular disorder, edema of the foot or ankle, refusal to participate in the study.

**Methods:** Participants will be evaluated in sitting, standing, and ambulation with bare feet, an orthosis with polyurethane closed cell foam padding, and an orthosis with gel padding. Using the Force Sensor Analysis (Verg.Inc.) pressure mapping system in each of these conditions pressure will be recorded at baseline and after two weeks of wear. The areas being measured include bilateral malleoli, navicular tuberosity and the lateral aspect of both the first and fifth metatarsal heads.

**Data Analysis.** ANOVA for repeated measures will be used to determine if pressure differences for each prominence and for total pressure are significantly different for each condition. Alpha will be set at 0.05.

**Results:** To date – two subjects have completed the study. A significant difference was found in the walking condition for total pressure with gel versus the non gel orthosis ( $\pm$ SD;p=.008) at baseline.

**Conclusions:** Initial trends with one subject appear to indicate that under conditions where the subject exerts more pressure (ie. walking) gel padding is significantly better at reducing overall pressure within the orthosis than foam padding. Initial percent changes within one of the subject's data has shown decreased pressure in the sitting, standing, and walking baselines. This may assist in building an orthosis that will be better tolerated.

### **PROSTHESIS FOR CAUDAL REGRESSION SYNDROME**

*Sherryl Nash, CO, BEP  
Texas Scottish Rite Hospital for Children, Dallas, Texas*

CM is a 2-year-old boy who has a diagnosis of multiple congenital anomalies, caudal regression syndrome and sacral agenesis. Elective above-knee amputation on the basis of deformity of the lower limbs was accomplished at the age of 1.

The patient has bladder and urinary problems secondary to caudal regression syndrome and sacral agenesis. He also has significant muscle weakness in his trunks and hips. Patient has also had three releases for tethered cord syndrome.

The patient was initially seen in our facility at age 1. The initial prescription was for stubby type prostheses which could be worn with a custom soft belt fit with chafes. With this system, however, he was unable to perform a consistent "swing-through" gait.

His hips were widely abducted because of weakness in the hip adductors and extensors and the "natural" abducted position of the hip joints due to the sacral agenesis. He lacked gait independence.

**Fabrication Details:**

- Bilateral metal plates with growth extenders have been added to the hip joints in the lamination in order to allow for patient's growth.
- Bilateral thrust bearing hip joints are attached to a custom pelvic belt that has been fashioned out of aluminum.

**Secondary Suspension:**

- Posterior chafes are affixed as shown to the midline of the pelvic belt and suspenders are attached thereto.
- Caudal regression patients like CM have a typically "flattened derriere", and this secondary suspension aids in lifting the child while maintaining the prosthesis on the limbs.

**Height Considerations:**

- The prosthesis needed to be short enough to allow patient to stand from a flexed hip position with hands down on the floor.
- The prosthesis needed to be long enough to give patient a semblance of normalcy in height alongside his classmates.

**Fabrication Details:**

- The abdominal support consists of chafes riveted to the pelvic band on each side and felt padding sewn to a Velcro/Dacron belt.
- Low profile sockets are lined with custom Bocklite liners and do not come up to the perineal area at all in order to allow patient to potty train. Toddler Pull-Ups can be placed over the prosthesis to allow for more independence for the patient.
- Patient's fit in the prostheses is managed with sock ply. Patient is currently in 5 ply socks bilaterally. Suspension is through the use of Medium Pediatric Neoprene Sleeves.

Similar Case found in 1984 JACPOC: Sacral Agenesis Prosthetic and Physical Therapy Management of a Patient with Sacral Agenesis; Lawrence Moraw, M.D., author; Detroit Institute for Children Detroit, Michigan

**Acknowledgements:** I would like to acknowledge the assistance and expertise of Don Cummings, CP, and Steve Ronde, CPO, for assisting with selection of this treatment protocol.

**A UNIQUE APPROACH TO AMBULATION  
FOR THE MORE SEVERELY INVOLVED CHILD WITH OSTEOGENESIS IMPERFECTA**

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One of the most challenging tasks facing a young child with moderate to severe Osteogenesis Imperfecta is learning to ambulate in the presence of fear knowing that a simple fall could yield devastating results. An additional challenge facing this population is the predisposition for rapid weight gain due to a lack of physical activity. Out of a necessity to provide a means of ambulation without risk of falls that does not require constant hands on assistance, a creative solution was designed. By utilizing an existing piece of equipment designed for the Cerebral Palsy population and modifying the bracing components, a suspension-type of hands-free ambulation makes walking a functional means of mobility for the 6-year old subject of our case study. In this device, he has progressed to ambulating at least a ¼ mile each day in school. Additionally, he is able to independently play games such as tag and kickball with the children on the playground and in his neighborhood. Improvements continue to be made as he demonstrates greater strength and desires more freedom of movement. This creative solution has surpassed

our expectations and shows promise for safe, independent ambulation for a population that is often limited to only therapeutic assisted ambulation.

There would be an accompanying video of the subject playing with his peers in the device. The subject, himself, would also be present.

### **TREATMENT OF CRANIOPAGUS TWINS WITH CRANIAL REMODELING BANDS**

*Timothy R Littlefield, MS; Jeanne K Pomatto, CO, BOC  
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Conjoined twins are formed when a developing embryo begins to split into identical twins, but for unknown reasons stops part way. Conjoined twins occur approximately once in every 200,000 live births, and are typically classified by the anatomical location where they are joined. *Craniopagus* twins, twins joined at the cranium, are exceptionally rare occurring in only 2% of conjoined twin cases or roughly one in every 10 million live births. Separation of craniopagus twins is often a very controversial and risky procedure due to the high rate of mortality and morbidity associated with this procedure.

In 2002, a set of Egyptian craniopagus twins were flown to the International Craniofacial Institute in Dallas Texas to be evaluated for possible surgical separation. While a battery of tests confirmed the significant complexity of this procedure, surgeons were optimistic that separation could be successfully achieved. This resulted in the development of a highly customized and intensive surgical and treatment plan, requiring the expertise of many medical specialties.

Part of the treatment plan included the use of specially designed cranial remodeling bands preoperatively. These devices were developed to prevent further deformation of the infant's skulls which had already become significantly misshapen due to their unique constraints. Following surgical separation, new cranial remodeling bands were designed to protect the infants' brains until the missing cranial vault of both children could be reconstructed.

In this presentation we will share the treatment objectives and outcomes, and discuss the many unique challenges that were faced during the design, fabrication and fitting of these devices.

### **BRIDGING THE UPPER EXTREMITY PROSTHETIC GAP**

*Heather Hoyt, OTR/L  
OttoBock Health Care, Minneapolis, MN*

It has long been recognized that there exists a gap in product availability for limb loss patients as they grow from pediatric to adult sizes of Myoelectric hands. This deficit results in patients leaving myoelectrics or prosthetics in general because of the lack of sizing. This can be frustrating for the patients and counter productive to all of those learning to do two handed activities. Another common problem is that petite individuals have not had a satisfactory size of hand to fit their body image. This again makes what would be a viable option for this individual impossible and as a result, they may choose not to have a prosthesis. In recognition of this need, a current solution is now available. There is a myoelectric hand appropriate for adolescents and petite adults with upper extremity limb loss that offers many special benefits, including cosmesis, a high pinch force, less weight and a unique design structure that allows for better fine motor pinch of small objects. This presentation will examine the benefits of a smaller size adult terminal device, including increased compatibility for a broader user base (particularly for adolescents and petite adults), cosmesis, high pinch force and a distinctive structural design, allowing for increased fine motor pinch.

### **USE OF PROSTHESES BY CHILDREN WITH MYELODYSPLASIA AND LOWER EXTREMITY AMPUTATIONS**

*Rodney Alan, MD; Jean Brown MS, RN; Linda Pugh, BS; Peter Stasikelis, MD  
Shriner's Hospital for Children, Greenville, SC*

Patients with myelodysplasia sometimes require amputation for severe deformity, chronic ulcers, or infection. The function of these patients after amputation is unknown. This study investigates the use of lower extremity prostheses by patients with myelodysplasia who have undergone amputation. We performed a retrospective chart review of all patients with myelodysplasia who had an amputation at a children's orthopaedic hospital. We contacted patients to inquire about the use of their prosthesis and their function. No patient had a decline in functional level after amputation. At an average follow-up of eight years, every patient with a below knee level amputation wore their prosthesis. Most reported having ulcers on their residual limb, but continued to use their

prostheses. 83% of patients felt that their lives had been improved after amputation while 17% felt that their lives were unchanged. We conclude that patients with myelodysplasia who have had amputations can successfully wear prostheses and maintain the same level of ambulation.

## **DEVELOPMENT AND CLINICAL TESTING OF A NEW STANCE-PHASE CONTROLLER FOR PAEDIATRIC PROSTHETIC KNEE JOINTS**

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Stance-phase control refers to the amputees' ability to control the articulation of a prosthetic knee joint while weight-bearing. It is influenced by several factors including prosthetic alignment, the physical condition of the amputee, and in large part the performance of the prosthetic components, specifically the prosthetic knee joint mechanism. Despite some major technological advancements in the design of paediatric prostheses in recent years, children with above-knee and through-the-knee amputations do experience occasional falls. This occurs as the knee joint becomes unexpectedly unstable, during standing, walking or running, and results in the child stumbling and/or falling. Previous studies indicate that stance-phase stability is a highly important functional requirement amongst the paediatric amputee population and that a reduction of incidents of falls is desired.

A prosthetic knee joint with a new stance-phase controller was developed to provide increased stability during weight-bearing. The knee joint utilizes a lock that is engaged upon the extension of the knee joint at the end of swing-phase, and remains locked through heel-strike and mid-stance. Towards the end of the stance-phase, as the forefoot becomes loaded, the lock is automatically disengaged allowing the knee to flex. Prototype knee joints were constructed and cyclically tested for reliability and durability using an in-house-built gait simulator, applying heel-strike loading, push-off load and swing-phase knee flexion.

Six children, ages 7 to 13 years, with above-knee amputations were fitted with the prototypes. Three of the six children had a below-knee amputation on their contra-lateral limbs. Performance of the knees was evaluated to help determine whether the added stability helped to decrease the frequency of falls, and whether it resulted in altered gait. Functional aspects, including the incidence of falls, were reported using a questionnaire developed specifically for the study. Differences in gait between the prototype and conventional prostheses were measured in a gait laboratory equipped with three-dimensional motion tracking and two force platforms.

From the questionnaires, no differences were reported in terms of the types of activities that the children were able to perform with the prototype and conventional prosthetic knee joints. However, all the children reported a lower incidence of falls with the prototype knees. Five of the six children reported that they no longer fell. All children also reported that they felt more secure and more confident that the knee would not collapse. All children preferred the prototype knees above their conventional paediatric prostheses. No significant differences were observed in the temporal, spatial, kinematic or kinetic gait parameters between prototype and conventional knees suggesting that the increased stability does not adversely affect gait.

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### **GROSS MOTOR ACTIVITIES OF DAILY LIVING AS A MEANS OF ASSESSING PROSTHETIC FUNCTION**

*Martha Ross, BSc,Eng<sup>1</sup>; Edmund Biden, PhD<sup>1</sup>; Victoria Chester, PhD<sup>2</sup>; Wendy Hill, BSc,OT<sup>1</sup>; Greg Bush, CP(c)<sup>1</sup>; Maureen Tingley, PhD<sup>3</sup>; Laura Brown<sup>1</sup>*

*<sup>1</sup>Institute of Biomedical Engineering; <sup>2</sup>Faculty of Kinesiology; <sup>3</sup>Dept. of Mathematics and Statistics, University of New Brunswick, Fredericton, NB, Canada*

Few studies have examined the upper limb movement patterns in amputees and even fewer have used motion analysis to assess prosthetic function. The purpose of this study was to differentiate between upper extremity prosthesis wearers and normally limbed children by measuring upper limb movement patterns during gross motor activities. Clinicians on our team have observed subjectively that the Omni-wrist, a friction wrist with three degrees of freedom, allows the user to exhibit more natural positions during certain activities than with a wrist that allows only axial rotation, however; this has not been measured

VICON M-Cam, an optical motion analysis system, was used to perform a motion analysis study. Reflective balls were adhered to the upper body and tracked using video. Normally limbed children between the ages of 4 to 13 were invited to participate (N=19). These children were used to define means and ranges of motion for the arms during four gross motor activities: riding a scooter, batting a baseball, zipping a vest, and swinging on a swing.

These activities were chosen because they involve wrist movements and are challenging for prosthesis wearers. The study design allows for the comparison of children using upper limb prostheses, against normally limbed children on either a case by case basis or as a group.

Normative data has been collected and amputees are enrolled as they become available. To date, four below elbow amputees wearing myoelectric prostheses have participated. Two children had Omni-wrists and two had a wrist with only axial rotation. All children were asked to perform the activities. The Omni-wrist wearers performed the test twice 1) full wrist range of motion 2) only wrist axial rotation.

Preliminary data analysis has focused on two activities: zipping and swinging. Compensatory motions of the shoulder and trunk are present in all prosthesis wearers. For example, when swinging, the shoulder on the prosthesis side is moved back relative to the sound side to allow grasping of the rope with the prosthesis. The Omni wrist appears to require less compensation, but asymmetry is still present when compared to the same measures in normally limbed children. For the zipper, the prosthesis wearers assume awkward postures which may contribute to the longer times they need to accomplish the task. Motions used by amputees during the activities are notably different from those in the normative group. Range of motion (ROM) is reduced on the affected side, the patterns of movement during the tasks are altered, and body posture is more asymmetric.

Quantitative measurements enhance observations by clinicians. Table 1 shows the mean ROMs for normally limbed children during swinging for four body angles. Results for prosthesis wearers are demonstrated on an individual basis and it is apparent that ROMs are reduced compared to the normally limbed group. In this case, our preliminary results suggest that while the Omni-wrist may produce movements which are more natural but there is still asymmetry in the motions.

Table 1 Swinging Activity: Mean ROMs for normally limbed children and prosthesis wearers for four upper body angles (angles in degrees)

Normally Limbed (N=19)		Right Side Elbow Flexion (SD)	Left Side Elbow Flexion (SD)	Right Side Wrist Flex/Ext (SD)	Left Side Wrist Flex/Ext(SD)
		69.5 (21.8)	70.2 (22.5)	41.0 (15.3)	45.3 (19.5)
Prosthesis Wearers (N=6)		Non Prosthesis Side	Prosthesis Side	Non Prosthesis Side	Prosthesis Side
Axial Rotation Wrist Wearers (N=4)	Child 1	5.3	5.6	4.7	2.8
	Child 2	11.9	28.2	36.1	4.8
	Child 3	29.1	39.9	22.2	4.2
	Child 4	28.3	47.3	41.0	6.3
Omni-Wrist Wearers (N=2)	Child 3	31.1	60.7	39.7	7.2
	Child 4	50.7	31.2	15.6	10.3

This study is ongoing and will include more children, both normally limbed and prosthesis wearers, and an analysis of all the tasks.

### MANAGEMENT OF FOCAL GIGANTISM BY FOOT ABLATION, DISTAL BK AMPUTATION AND OSTEOCARTILAGINOUS “CAPPING” OF TIBIA AND FIBULA: A CHALLENGING CASE PRESENTATION

*Robin C Crandall, MD, Director of Amputation, Prosthesis Clinic  
Shriners Hospital for Children, Minneapolis, Minnesota*

FK, a 3+11 year-old Native American male was born with unilateral right leg hemihypertrophy and focal gigantism of the entire right foot and ankle. At age 12 months he underwent debulking of the foot by central ray amputation. In spite of the surgery, he was still unable to don an footwear and was first seen in consultation at the Minneapolis Shriners Hospital for Children at age 2+2. A Syme amputation was carried out at 2+8, which proved useful for ambulation but still inadequate for satisfactory prosthetic fit due to soft tissue bulk. Stump revision via distal below the knee amputation with debulking and osteocartilaginous capping with syndesmosis creation of the residual tibia/fibula was carried out at age 3+8. Etiology and problems associated with focal gigantism syndromes will be discussed.

## **TIMING AND DECISION MAKING IN A CHILD WITH ARTHROGRYPOSIS AND UNILATERAL KNEE DISARTICULATION**

*Ann C Modrcin, MD\**; *Loren J Decker, MA, Prosthetist\*\**

*\*Children's Mercy Hospitals and Clinics, Kansas City, MO; \*\*Capital Orthopedic Center, Lenexa, KS*

**The Problem:** This case involves a 4 year, 6 month old girl with a history of arthrogyrosis and congenital knee disarticulation amputation. She has a knee extension contracture on the contralateral side and limited wrist and hand motion bilaterally. Overall, the patient's leg strength is adequate on both sides. Cognitive function is normal.

Surgical intervention for the knee extension contracture is being contemplated, as her restricted range of motion prevents her from achieving optimal mobility and functional transfers. The patient is dependent on others to don and doff the knee disarticulation prosthesis secondary to limitations of range of motion and strength in her hands.

**Issues for Discussion:** The case study will review this patient's anatomy, both clinically and radiographically; her functional limitations and potential challenges that will likely progress with growth. These challenges need to be addressed in a timely manner. Her restricted upper extremity range of motion at the shoulder, elbow and wrist, along with impaired hand function limit her potential for independence with donning and doffing of the prosthesis. Functional skills, such as transfers and getting off the ground independently are also impeded by her joint limitations.

A review of literature will be included. The patient's surgical and prosthetic interventions will be discussed. The goal of presenting this patient will be to seek expert opinions regarding management strategies and timing of orthopedic and prosthetic interventions for this rare combination of conditions.

## **OVERCOMING PHYSICAL BARRIERS TO OBTAIN INDEPENDENT MOBILITY**

*Mike Bobala, Seating Specialist; Suzanne Weiss, MSC, CCC-SLP*

*Shriners Hospital for Children, 12502 Pine Dr. Tampa, FL*

Stephen is a 19-year-old male four years post anoxic brain injury. He has been followed over the last two years as a potential power mobility candidate. This case study will present the complex issues faced by the power mobility team to achieve successful independent driving skills. Challenges faced for seating and positioning, consistent access, and memory/response time will be presented with the solutions developed in the team process.

## **AMPUTATION-FIRST STEP TO A BETTER QUALITY OF LIFE**

*Owen A. Larson, CP*

*Artificial Limb Specialists, Mesa, Arizona*

This 13+9 yr old white female was a product of a normal pregnancy and delivery. Some dysmorphic findings at birth, including web toes, and a single crease in the palm. There were no other obvious findings. Eventually she developed Neavei, which were linear in function, and by the age of three the diagnosis of epidermal nevus syndrome was made with hemi-hypertrophy on her right side compared to the left.

At the age of 3 in 1992 her leg length discrepancy was 1.4 cm. By the age of 9+6 she had a discrepancy of 4.5 cm. Leg lengthening was discussed at this time. At the age of 10 she underwent leg-lengthening procedure of her left leg. She had both femoral fixator and a tibial fixator applied at the same time. Immediately after surgery she was unable to move her toes or ankle on her own. Her foot became hypersensitive; the slightest touch would create pain. Five days into the lengthening process daily adjustments had to be stopped.

She was unable to tolerate the pain. After a few days of rest the adjustment were increased to 4 times a day.

One month post-op an exploration of the peroneal nerve was done. It was found to be intact with some bleeding and edema with resultant scar. Once again the adjustments had to be stopped due to pain. At this time a pain management specialist was called in.

Eight months post-op the lengthening procedure was aborted due to extreme pain. Only 1.5 inches had been gained. Three inches was the original goal. Also at this time an Achilles lengthening was preformed. When the cast

was removed she had a significant ulcer which took considerable time to heal. Over the next twenty-one months a number of Orthotic devices were used each prohibitive due to pain or soft tissue breakdown.

In May 2001 at the age of 11+9 months she underwent a medial and lateral hamstring release as well as another Achilles lengthening. After surgery she had lost all movement she had gained and no longer had feeling in her foot, ankle or lower leg. She ambulated in various manners depending on the distance she had to travel. Assistive devices included wheelchair, walker and cane.

In April of 2003 the option of amputation was discussed. The family met with amputees of same sex and age. A meeting set with the doctor, family and Prosthetist to discuss surgery and rehab. In September 2003 an above knee amputation was performed.

At 6 weeks post-op she was cast for a temporary Prosthesis. Fitted the following week and scheduled for physical therapy. After one week of therapy she walked without any assistance of any kind.

Currently the patient is an active high school student leading a better quality of life through amputation.

### **CLINICAL OUTCOMES ASSESSMENT OF CHILDREN WITH UNILATERAL CONGENITAL BELOW ELBOW DEFICIENCY (UCBED): A MULTI-CENTER STUDY**

*Michelle James, MD; Anita Bagley, PhD; the UCBED Study Group\**  
*Shriners Hospitals for Children, Northern California, 2425 Stockton Blvd., Sacramento, CA 95817*

The purpose of this symposium is to present the results of a multi-center study of 494 children with unilateral congenital below elbow deficiency. In this cross-sectional study, children and their parents were asked to complete questionnaires regarding prosthetic use and satisfaction, quality of life, and general musculoskeletal health. In addition, all children performed a test of bimanual function; prosthesis wearers performed the test both with and without their prosthesis.

The speakers will discuss how prosthetic use relates to function and quality of life. Data will be analyzed based on age at first fit, training, type and number of prostheses prescribed. Confounding variables, such as residual limb length and pinch strength, will be examined. Reasons for not wearing a prosthesis will be discussed.

*\* Participants from 10 Shriners Hospitals for Children: Erie (Katherine Brasington OTR, Sharon O'Connell MS), Greenville (Lisa V. Wagner OTR), Houston (Joanne Libertore OTR, Becky Ligon OTR, Elroy Sullivan PhD), Los Angeles (Joanna Patton OTR, Joanne Shida OTR), Montreal (Kathleen Montpetit BScOT), Northern California (Leslie Clawson MSW, Cheryl Hanley OTR, Carrie Risi-Hart OTR), Philadelphia (Susan Duff OTR, Cheryl S. Lutz OTR), Springfield (Elaine Charest OTR), St. Louis (Loray A. Dailey, OTR), and Twin Cities (Wendy A. Tomhave OTR) under the direction of Anta M. Bagley PhD and Michelle A. James MD.*

### **WREX: AN UPPER EXTREMITY FUNCTIONAL ORTHOSIS**

*Tariq Rahman, PhD; Shanmuga Jayakumar, MD; Whitney Sample, BS; Marnie King, BS*  
*Alfred I. duPont Institute, Wilmington, Delaware*

Children with arthrogryposis often exhibit limited movement and strength in their elbow. This is most pronounced in anti-gravity movements such as when bringing food to their mouth. These children often resort to compensatory movements by using the contralateral hand as a support, or using gravity to flex the elbow by overflexing the shoulder thereby bringing the food down. These movements, although effective, are awkward. We present a new functional orthosis that is worn by the child. WREX (Wilmington Robotic Exoskeleton) is an elastic band powered upper-limb orthosis that provides full range of 3-D movement to a child with weak elbow and shoulder muscles. It is light enough to be worn on a torso brace and eliminates gravity-induced limitations in the upper arm and forearm.

WREX has two links (upper arm and forearm) and four degrees of freedom. The upper arm link consists of a parallel bar. It uses elastic bands to counter gravity, allowing three-dimensional hand movement. People of different weights can be accommodated by changing the number of elastic bands. The lengths of the links can be adjusted to suit different sized individuals. The arm trough and torso brace are also made especially for each subject by casting the arm and torso with plaster, fabricating a positive mold, and finally making a negative polyethylene

brace. A 6-year old girl with arthrogryposis and no elbow flexion has been wearing WREX for 3 months. She is ambulatory and dons WREX for three meals a day. It has made a considerable impact on her quality of life.

We present the design and manufacturing of WREX along with experience with 16 subjects. WREX has been also used for children with muscular dystrophy and spinal muscular atrophy. In these cases it was attached to their wheelchair. Results will be reported for 15 children who used WREX for extended periods mounted to their chairs. They participated in the Jebsen test of hand function before using WREX and then with the aid of WREX. The times for the Jebsen were decreased significantly for most of the children.

## **UPPER LIMB PROSTHETIC EXPERIENCE WITH CORNELIA DE LANGE SYNDROME**

*J Thomas Andrew, CP, FAAOP*

*Ability Prosthetic Systems, Inc, Salt Lake City, Utah*

Cornelia de Lange syndrome (CdLS) is a rare developmental malformation condition affecting from 1 in 40,000 to 1 in 100,000 babies born and characterized by developmental delay, growth retardation, limb reduction abnormalities and dysmorphic facial features. Diagnosis is dependent on the recognition of the distinctive facial features.

A 1993 study of 310 individuals with diagnosed CdLS showed that only 27% had the upper limb deficiencies commonly associated with the syndrome. In more severe upper-limb involvement, fingers, metacarpals and the long bones of the arm are absent. However, the use of upper limb prostheses for children afflicted with CdLS is rare. Most of the literature does not mention prosthetic fitting, or mentions it in a negative way.

The effects of the syndrome are broad.

An average IQ score *in individuals able to be tested* has been found to be 53, which is within the mild to moderate range of mental retardation.

Developmental skills are often delayed. Early intervention is indicated as soon as a diagnosis is made, since it appears to play a major role in the level of achievement.

Developmental areas of strength include visual-spatial memory and perceptual organization. Thus the use of computers, using visual memory, may be of benefit over standard methods of verbal instruction, as may tactile stimulation. Language is an area of weakness, and may be compounded by hearing abnormalities. Fine motor activities should be stressed in education, especially those related to activities of daily living.

This visual-spatial memory and tactile stimulation may be why prosthetic fitting of the appropriate type appears to be reasonably successful. These individuals "discover" how to use the prosthesis rather than having instruction in a formal way.

The absence of speech or the development of only minimal speech has been well documented, even in the more mildly affected. The majority of individuals are very quiet. They frequently make eye contact and there is often a sense that they understand what is being said, but they are not usually vocal. We believe that there is more understanding of the prosthetic process and use than can be documented by verbal feedback.

It has been suggested that one reason for the low rate of upper limb prosthetic fitting attempts of children with CdLS is that they are not expected to have the intellectual skill to master prosthesis control and become proficient in its use.

From a developmental perspective, with prehensile limbs, a CdLS patient can have more normal experiences to build visual spatial sensory skills and improve intelligence. These experiences are critical to acquiring further skills and knowledge.

We have shown that, in some cases, unique socket designs coupled with the creative use and early fitting of an appropriate voluntary opening / automatic closing externally powered components and custom control methods can provide these children with useful function that increases their independence and improves their lives.

Among many skills, our patients have successfully learned to feed themselves using their prostheses. This not only benefits them but also their caregivers.

## **FIVE YEAR POST-OP FOLLOW-UP OF TWO CHILDREN WITH RECONSTRUCTION OF THE PROXIMAL HUMERUS USING THE ROTATED CLAVICLE AFTER EXCISION OF MALIGNANT TUMORS**

*Mei F Fong, BSc, PT; Christina NYu, BSc, OT; Gerhard N Kiefer, MD; James A Harper, MD  
Alberta Children's Hospital, Calgary, Alberta, Canada*



The proximal humerus is one of the primary sites of malignant tumors in the upper extremities. Traditional treatment with forequarter amputation has been traumatic for loss of bilateral hand function and poor cosmesis. In the past decade, treatment of childhood malignancy has changed radically with intensive chemotherapy as part of the multimodality treatment, making limb salvage surgery possible.

The primary goal of limb salvage for upper extremities is to preserve elbow and hand function after excision of tumors at the proximal humerus, even though the shoulder remain flail with limited active range of motion. Other surgical procedures have also been used for this condition, such as allogeneic grafts and endoprostheses.

The focus of this poster is on the reconstruction of the proximal humerus using the rotated clavicle of two patients aged 11 and 15, diagnosed with osteosarcoma. This procedure provides stable shoulder joint, biological surfaces for soft tissue reattachment and, most importantly, the possibility for further limb growth in children.

The surgical procedure includes:

1. Excision of tumor at proximal humerus
2. Detachment of clavicle from sternum with downward rotation and attachment to the distal humerus
3. Reconstruction with Latissimus Dorsi as musculocutaneous flap

Discussion will focus on the post-op rehabilitation and five-year evaluation of shoulder, elbow and hand functions, and complications with non-union at the junction of the clavicle and humerus, arm length discrepancy, and asymmetry of shoulder contour.

## **AN OVERVIEW OF RGO AND HKAFO USE IN PATIENTS WITH MYELODYSPLASIA**

*Ken Guidera, MD; Janet Marshall CPO; Sandra Smith, MSPT  
Shriners Hospitals for Children, Tampa, Florida*

Children with thoracic and high lumbar myelodysplasia commonly require RGO and HKAFO to allow ambulation. Integration of these orthoses for functional ambulation and activities of daily living can vary secondary to multiple factors, including age, wearing patterns, orthopedic deformity, supervision required to walk, difficulty to don and doff the device, and perceived exertion. The Tampa Shriners Hospital interviewed 43 patients of different ages to determine utilization and wearing patterns. Only 26% wore their orthosis greater than four hours per day and most did not wear them daily. These results question the cost effectiveness of prescribing these braces, especially in the growing child. The clinic teams from Tampa Shriners Hospital and Children's Healthcare of Atlanta will review prescription practice, training and outcomes related to these orthoses. A discussion of alternatives for upright mobility and determination of what is considered "successful" use of all available devices will include audience participation.

## **PRE-SURGERY EDUCATION FOR CHILDREN AND FAMILIES AT THE CENTER FOR LIMB DIFFERENCES**

*Beth Terborg, BSN*

*Center for Limb Differences, Mary Free Hospital and Rehab Center, 235 Wealthy SE, Grand Rapids, MI 49503*

Because outpatient surgery or same day surgery has become the most common form of surgery for children in the United States, the responsibility for pre-surgical education has shifted from hospital staff to outpatient clinic staff. This poster presentation covers reasons why pre-surgical teaching is so important. It also includes general information for all families, and age-specific information for children based on their developmental level. Important considerations for teaching each age are discussed as well as specifics for each age group that can make hospitalization and surgery a little easier. Included are written resources and illustrations of specific toys and other

equipment that we at the Center for Limb Differences have found helpful. A list of websites and other sources are given so that other clinics, who might wish to, can look for what resources may be helpful to their patients and families.

### **DESIGN AND USE OF A HIP CRADLE ORTHOSIS FOR PEDIATRIC POST PROXIMAL FEMORAL RESECTION PATIENTS**

*Timothy A Finlan, MS, OTR/L; Sandra B Smith, MSPT  
Shriners Hospitals for Children, Tampa, Florida*

Pediatric patients with quadriplegic cerebral palsy who undergo a proximal femoral resection experience increased pain and discomfort during movement of the lower extremities. This pain and discomfort is exacerbated during transfers, such as from bed to wheelchair, wheelchair to toilet, as well as change of position for pressure relief. The pain and discomfort is believed to be due to movement of the femur within the inflamed soft tissue of the thigh area resulting in distress not only for the pediatric patient, but for the family and caregivers as well.

Therapists at Shriners Hospitals for Children, Tampa Hospital, have developed a low temperature orthotic device that supports the resected hip posteriorly, from the buttocks superiorly, down the thigh, ending proximal to the knee joint inferiorly, attached with velcro straps. The removable Hip Cradle is an alternative to spica cast immobilization. Besides providing the needed stability at the hip for more comfortable transfers and positional changes during the acute post-operative recovery period, there is added benefit of allowing range of motion, skin monitoring and ease of activities of daily living and hygiene. Case studies will be presented to demonstrate the use and application of the Hip Cradle as well as the reported satisfaction by the patient/family.

### **TWO MODELS OF A LOW-TEMPERATURE WRITING DEVICE FOR A CHILD WITH FINGER DEFICIENCIES**

*Toni Thompson, MA, OTR/L, BCP*

A pre school child, Tanner, with finger deficiencies of only two digits, both short, stabilized and managed writing tools, such as pencils, crayons, markers, and paint brushes with the distal aspects of both hands. He was unable to maintain a sufficient grip on the objects using the two digits of either hand. Using both hands to manage a writing tool does not allow one limb free to perform age-appropriate tasks, such as stabilizing or moving the writing surface, or raising a hand to ask the teacher a question.

His father a graphic designer, conceptualized several options to hold a writing tool for his son, including a few designs that attached to the forearm with Velcro.

Current commercially available tools accommodate one size of writing tool, usually a standard pencil, but not a marker or crayon. Other commercial designs require a great of time to change the tool being held.

Tanner, his father, and his occupational therapist collaborated to develop a device that:

1. Held a writing tool in place using only one upper extremity,
2. Allowed the non-dominant limb free to stabilize and move the paper,
3. Accommodated to writing tools of various shapes and sizes,
4. Allowed easy and quick changes of writing tools by an adult,
5. Can be easily donned and doffed,
6. Was aesthetically pleasing.

Tanner used the original device, nicknamed the "Tanner-Saurus", fabricated of low-temperature thermoplastic material for a forearm base, low-temperature tubing and cylindrical foam, for a year during pre-school. After one year, the Tanner-Saurus team developed an improved, more low-profile model, the "Tanner –Saurus Two." Both the Tanner-Saurus and the Tanner-Saurus will be presented.

### **UNDERSTANDING THE EFFECT OF THE TOTAL MASS AND THE DISTRIBUTION OF THAT MASS ON THE NATURAL SWING PERIODICITY OF THE PEDIATRIC TRANSFEMORAL PROSTHETIC SHANK**

*Phil Stevens CO, BEP  
Dynamic Orthotics and Prosthetics, Houston TX*

A prolonged prosthetic swing phase has been identified as a common problem among pediatric transfemoral amputees. This leads to either reduced self-selected walking speeds or asymmetric timing in gait. Modeling of prosthetic shanks can be performed according to both physical and mathematical frameworks. These models predict certain relationships between mass and mass distribution on the inherent swing periods of pediatric prosthetic shanks. Analyses were performed based on a simple pendulum model and using second order differential equations. Conflicting predictions result. Swing periods of a sample pediatric shank were timed while mass and distribution of mass were varied to determine which of the two modeling methods corresponded to collected physical data. While models predicted considerable changes to swing phase durations, collected data indicate that reasonable variations to both mass and its distribution fail to substantially effect the natural swing period of the pediatric prosthetic shank. Recommendations for future study are presented.

### **DESIGN AND USAGE OF A MYOELECTRICALLY CONTROLLED ORTHOSIS FOR SEVERE BRACHIAL PLEXUS INJURY**

*Ann C Modrcin, MD\*; Stephen Mandacina, CP, FAAOP\*\*; Keith Andrews, CP\*\**

*\*Children's Mercy Hospitals and Clinics, Kansas City, MO; \*\*Hanger Prosthetics and Orthotics, Inc, Anaheim, CA*

**The Problem:** This case involves an eight year old boy with severe left sided brachial plexus injury due to complications of shoulder dystocia at birth. He has undergone multiple surgeries and rehabilitation interventions. Despite these efforts has severe residual weakness of his left arm, especially of the lower trunk. Hence he has no active wrist or hand movement which markedly impairs his function.

Birth related brachial plexus injuries are common, with 1 to 2 per 1000 births resulting in some degree of weakness in the involved arm. Of those, most resolve with or without treatment, but about 10% of affected children are left with residual weakness, which is severe in some children.

A review of the literature did not demonstrate that a comprehensive orthotic approach designed for a child's specific residual impairment has been widely utilized.

**The Solution:** A team approach was utilized to assess the utility of a myoelectrically controlled orthosis for this child. We sought input from professionals from the Brachial Plexus Clinic and from the Limb Deficiency Clinic. Myoelectric prosthetics are a proven adjunct to function in individuals with congenital or acquired amputation. In this case, we are applying myoelectric technology in a novel fashion, orthotically rather than prosthetically.

This case study will review this patient's anatomy, his functional limitations, and the orthotic interventions that were designed for him. We will review his function objectively, with and without the orthosis.

The goal of presenting this patient will be to review our management strategy, discuss the design and fabrication of this device, and to discuss his outcome with this new application of proven technology. Consideration of the feasibility of a multi-site prospective study to objectively assess the usefulness of this orthotic application will be pursued.

### **A NOVEL NIGHTTIME POSITIONING DEVICE FOR A CHILD WITH NEUROMUSCULAR SCOLIOSIS**

*Ann C. Modrcin, MD\*; Tom Hetzel, PT\*\**

*Children's Mercy Hospitals and Clinics, Kansas City, MO; \*\*Aspen Seating*

**The Problem:** This case involves an eight year old boy with congenital muscular dystrophy and resultant neuromuscular scoliosis, which has been progressive. Due to concurrent respiratory insufficiency he has been intolerant of TLSO usage. Custom seating was utilized, though his curve progressed relentlessly.

The purpose of presenting this case is to highlight a new type of bracing technology, and explore its effectiveness.

**The Solution:** A nighttime custom positioning orthosis was fabricated, which places the child in sidelying, supporting him in a position opposite of his usual curve. The rationale was to provide a significant length of time each night out of his usual posture, with temporary reduction of the destructive forces which promote increasing curvature.

The device is well-tolerated, he sleeps better, with less night time discomfort. His curve has remained static since he has been using the device. The patient and family are pleased with the device.

**Discussion:** Progressive scoliosis is common with certain types of congenital muscle disease. This case demonstrates the need to be creative to meet a specific patient's needs, and to monitor the results of the intervention.

This type of device may be useful in a subset of individuals with neuromuscular scoliosis as an adjunct to traditional management strategies. A prospective study to objectively assess the usefulness of this orthotic application may be warranted.

### **WHEELCHAIR CUSTOM LOWER EXTREMITY SUPPORT SYSTEM FOR POST SURGICAL CAST APPLICATIONS**

*Craig A Kraft, BS, IT, Coordinator, Seating Department  
Shriners Hospital for Children, 12502 N Pine Dr, Tampa, Florida*

Post surgical cast applications for lower extremity (LE) orthopedic correction result in a wide array of positioning challenges. Standard wheelchairs, elevating footrests, or extension boards may not safely accommodate the child.

We have designed and implemented a quick release multi-axis adjustable LE system that attaches to a wheelchair and safely supports lower extremities in any position. We now sub-contract the fabrication of the metal components to reduce the in-house labor demands.

Wheelchairs with custom LE supports are necessary for timely discharge and community transition. Patient/family satisfaction is considerable when mobility and safety are not roadblocks to school, therapy, and recovery.

The benefits of this system improve patient care, safety, and satisfaction not only for the child/family but for the medical team as well.