AIS & Bracing: Proof of Regression and Outcomes Prediction

Gez Bowman BS O&P (UK)

Valley Orthopedic Technology, Van Nuys, CA, USA. LA Brace International, Duarte, CA, USA. Bowman Enterprise Services, Van Nuys, CA, USA



Gez Bowman

Short Bio of all Presenting Authors

Gez Bowman CO, MBAPO is a UK and USA certified orthotist working in Los Angeles, California. He is the owner and clinician for Valley Orthopedic Technology, President of LA Brace International and President of Bowman Enterprise Services. He is the developer of The LA 3D Brace and LA Pectus Brace, opPractice app and opHUB marketplace.

Abstract

There is little consensus in the medical community as to the required average daily wear time (ADW) for an effective scoliosis bracing treatment. Patients continue to be given a subjective value for the number of hours they need to wear their brace, ranging from 8 hours/day to 23.5 hours/day. However, multiple prior studies have shown that bracing outcomes are proportional to average daily wear time (ADW). In addition, other studies have shown that outcomes are proportional to in-brace correction (IBC) and that the amount of IBC varies considerably between the braces used and between orthotists. Recent studies have shown that regression of scoliosis can occur when sufficient ADW and IBC are achieved. Given these factors and making some simple assumptions we can determine a more mathematical approach to brace wear time, thereby removing the subjectivity of ADW from bracing treatment protocols. A mathematical formula has been developed and converted into code to allow for prediction of outcome based upon DWT, IBC and other mitigating factors. Comparing the actual results of several braced scoliosis patients with the outcome prediction numbers shows a significant correlation of the two values. Use of the prediction formula in the author's clinic has been found to help encourage compliance with brace wear time needs. Expanded use of this mathematical formula and code using the given values for IBC and ADW could be a useful tool for other treatment teams to predict outcome and, when a negative outcome is presented, show the need for changes to the treatment.

To knee or not to knee, that is the question

Dr Phoebe Scott-Wyard DO¹, Jennifer Woodard CPO²

¹Rady Children's Hospital - San Diego, San Diego, ca, USA. ²Hanger Clinic, Inc, san diego, ca, USA

Dr Phoebe Scott-Wyard

Short Bio of all Presenting Authors

Dr. Phoebe Scott-Wyard is a rehabilitation medicine specialist at Rady Children's Hospital-San Diego and an assistant professor at UC San Diego School of Medicine. She is double board-certified in pediatrics and physical medicine and rehabilitation. Originally from Maine, Dr. Scott-Wyard completed her undergraduate degree in behavioral biology at Johns Hopkins University before attending medical school at Western University of Health Sciences in Southern California. She completed a combined residency in pediatrics and physical medicine and rehabilitation at Cincinnati Children's Hospital Medical Center and University of Cincinnati. Dr. Scott-Wyard is especially interested in treating children with limb differences. Before joining Rady Children's, she served as the medical director of the Child Amputee Prosthetics Project clinic at Shriners Hospital in Los Angeles for six years. She is also the vice president for the Association of Children's Prosthetic and Orthotic Clinics, the only professional organization for pediatric amputee care. She has served as a volunteer for the Challenged Athlete's Foundation and Angel City Games.

Jennifer Woodard

Short Bio of all Presenting Authors

Jennifer is an ABC-certified prosthetist/orthotist for Hanger Clinic in the San Diego area. She worked in Biotech for 8 years before going back to school to become a prosthetist. She started at Hanger Clinic as a technician, then became a certified prosthetist and later a certified orthotist. Jennifer is a California native, who graduated from Oceanside High School, then University of California San Diego. Jennifer enjoys taking care of the simple people, and giving people the opportunity to go back to their lives after amputation.

Abstract

DF is a 2 y/o M with a history of amniotic band syndrome, affecting his right lower extremity, very short BKA and shortened femur. His distal extremity was complicated by separation of his fibula and tibia, in separate skin envelopes. Patient was noted to have active R knee extension, however limited flexion to 90 degrees with patellar reflex, therefore fibula to tibial transfer was recommended (modified Boyd amputation) with soft tissue transfer/graft to keep him as a below-knee amputee (with potential for lengthening). If fails, then patient would be a candidate for knee disarticulation amputation. MRI showed patellar tendon attached to proximal tibia. R below knee prosthesis with external hinges and thigh cuff ordered, however clinician recommended fitting with straight leg prosthesis first to work on standing and walking. Patient was successful, and then the team attempted to fit with a prosthesis with

knee flexion in order to prepare him for ambulation after surgical intervention. This presentation will review the case, as well as the different prosthetic options that were trialed.



Beyond 'Crip Camp': Impact of medical camps on children with limb difference and their families.

Dr Phoebe Scott-Wyard DO

Rady Children's Hospital - San Diego, San Diego, ca, USA

Dr Phoebe Scott-Wyard

Short Bio of all Presenting Authors

Dr. Phoebe Scott-Wyard is a rehabilitation medicine specialist at Rady Children's Hospital-San Diego and an assistant professor at UC San Diego School of Medicine. She is double board-certified in pediatrics and physical medicine and rehabilitation. Originally from Maine, Dr. Scott-Wyard completed her undergraduate degree in behavioral biology at Johns Hopkins University before attending medical school at Western University of Health Sciences here in Southern California. She completed a combined residency in pediatrics and physical medicine and rehabilitation at Cincinnati Children's Hospital Medical Center and University of Cincinnati. She served two years as a Peace Corps volunteer in Ecuador and is fluent in Spanish. Dr. Scott-Wyard is especially interested in treating children with limb differences. Before joining the limb clinic at Rady Children's, she served as the medical director of the Child Amputee Prosthetics Project clinic at Shriners Hospital in Los Angeles for six years. She is also the vice president of the Association of Children's Prosthetic and Orthotic Clinics, the only professional organization for pediatric amputee care. She has served as a volunteer for the Challenged Athlete's Foundation and Angel City Games.

Abstract

Medical camps have been around for decades and have recently been illustrated in the documentary "Crip Camp" which followed a group of teenagers with disabilities who met during a medical summer camp and ultimately led them to change the way the US government enforced the Americans with Disabilities Act. But what does the literature say about the long-term impact of these camps? Should we be promoting them to our patients and their families? This lecture will review the history of these camps, and the research associated with medical camps, including the short- and long-term impact on children and their families. Some examples of medical camps for children with limb difference will be highlighted, and resources provided for camps local to different regions.

Time needed: 30-60 minutes

Objectives:

Attendees will understand the history of camps for children with chronic medical conditions.

Attendees will be able to enumerate the short- and long-term benefits of camps for children with chronic medical conditions and their families.

Attendees will know how to access resources for medical camps for children and families with chronic medical conditions.

Defining and Applying the Complex World of Sensation to Clinical Care: Past and Current Paradigms.

Dr Jonathan Schofield PhD¹, Dr Wilssan Joiner PhD¹, DR Colleen Coulter PT DPT PhD²

¹UC Davis, Davis, CA, USA. ²Children's Healthcare of Atlanta, Atlanta, GA, USA



Dr Jonathan Schofield

Short Bio of all Presenting Authors

Dr. Schofield works to improve user acceptance and promote the seamless integration of humans and assistive medical devices, leveraging techniques in bio-robotic control and feedback, sensorymotor neural interfaces, and cognitive-perceptual neurosciences. The Schofield lab performs interdisciplinary research at the interface of mechanical and electrical engineering, neurosciences and rehabilitation medicine to address unmet clinical needs and understand how humans engage with intelligent technologies such as robotic prostheses and powered exoskeleton orthoses, among many others.



Dr Wilssan Joiner

Short Bio of all Presenting Authors

Department of Neurobiology, Physiology and Behavior, College of Biological Sciences Department of Neurology, School of Medicine, Center for Neuroengineering, Center for Neuroscience, University of California, Davis Dr. Joiner studies how we use different sources of information to aid behavior, ranging from visual perception to movement planning and updating. Specifically, he is interested in how external and internally-generated sensory information is integrated in healthy individuals, in comparison to certain disease and impaired populations (e.g., Schizophrenia and upper extremity amputees). Achieving this understanding may lead to better methods for diagnosing and treating impairments of the nervous system.



DR Colleen Coulter

Short Bio of all Presenting Authors

Dr. Coulter is a Board Certified Pediatric Clinical Specialist through the APTA practicing in the field of pediatrics for 49 years. For the past 41 years, Colleen has worked alongside of orthotists and

prosthetists being employed by the Orthotics and Prosthetics Department at Children's Healthcare of Atlanta. She is the team leader for the Limb Deficiency Program and has lectured nationally and internationally and published in peer review journals and books on topics relating to physical therapy interventions in children with limb deficiencies that include chapters in the Atlas of Prosthetics and Limb Deficiencies and Campbell's Physical Therapy for Children. Dr. Coulter also serves as the physical therapist in the Cranial Remolding Program at Children's Healthcare of Atlanta and was instrumental in co-authoring the 2013 and 2018 update of Physical Therapy Management of Congenital Muscular Torticollis: an evidence based Clinical Practice Guideline from the American Physical Therapy Association and the manuscript Developing Evidence-Based Physical Therapy Clinical Practice Guidelines. In 2004 she co authored the chapter Identification and Treatment of Congenital Muscular Torticollis in Infants in the 2004 supplement to JPO, Orthotic Treatment of Deformational Plagiocephaly, Brachycephaly and Scaphocephaly. In addition, she continues to lecture and published in peer review journals and books on topics relating to physical therapy interventions in children with torticollis and cranial deformations that include chapters in the Campbell's Physical Therapy for Children, Meeting the Physical Therapy Needs for Children, and Physical Therapy Case Files: Pediatrics In 2009, Dr. Coulter was awarded honorary membership to the Academy of Orthotics and Prosthetics and in 2012, the distinguished Bud DeHaven Award from the APTA Section on Pediatrics. She is an active member of the Section on Pediatrics of the American Physical Therapy Association and the Association of Children's Prosthetics and Orthotics Clinics, ACPOC. Dr. Coulter is an Assistant Adjunct Professor at Emory University's School of Medicine Department of Rehabilitation. Currently, Dr. Coulter serves on the Amputee Coalition's Scientific Medical Board and Upper Limb Advisory Council. Currently Dr. Coulter is the president of the Association of Children's Prosthetic and Orthotic Clinics, ACPOC. Dr. Coulter received an undergraduate Bachelor of Science degree from Boston University, a master's degree in Developmental Disabilities from Long Island University, and Doctor of Physical Therapy and Doctor of Philosophy degrees from Rocky Mountain University of Allied Health Professions.

Abstract

Children want to move; we all know that. Every day we observe children and adults with and without impairments accomplish amazing things. We were taught that the effective execution of every action we perform depends on the intimate relationships between sensory input and motor output. But is there more to this? As healthcare providers, do we have a true understanding of sensation and how sensation influences movement? Although the terms sensory input, sensory processing, and motor learning are frequently used without clear definition, the neuroscientific and behavioral phenomena behind these concepts are fundamentally important to a child's development. Sensory impairments can profoundly impact a child's motor capabilities; functional independence; and the way they learn, play, and participate in the environments that surround them. Thus, a clear understanding of the sensory motor mechanisms are perturbed can provide important insights to help inform treatment strategies and enhance outcomes for these children.

The purpose of this symposium is to take a deep dive into the complex world of sensory-motor interactions that influence movement. Beginning with defining sensation and types of sensory input, the speakers will present on how sensory inputs integrate or interact with each other and influence movement with application to patient health conditions, interventions, and research.

Objectives- Upon completion of this symposium, participants will gain understanding on how:

- 1. Sensory information (e.g., visual, proprioception, kinesthesia) is used to plan and execute goal directed movements.
- 2. Predictions about the sensory feedback we experience from our actions influence movements.
- 3. Predictions when we experience errors (i.e., adaptation) impact movement.
- 4. Based on research and published literature, clinical conditions and neuro-motor deficits impact movements.
- 5. Sensation relates to prostheses use (cutaneous touch/force, proprioception vs. kinesthesia, etc).
- 6. Sensory restoration techniques improve prosthetic control with adults and how this necessitates a call to action for children's care.
- 7. The combination of intuitive control and sensation together can not only improve functional outcomes, but also restore the sense of a truly integrated limb replacement (embodiment).

A new foot orthosis design for children with Charcot-Marie-Tooth and impact on gait

Melissa Martel M.sc^{1,2}, Audrey Parent PhD³, Carole Fortin PhD^{4,2}, Laurent Ballaz PhD^{1,5}

¹Sainte-Justine Research Center, Marie-Enfant Rehabilitation Center, Montreal, Quebec, Canada. ²Université de Montréal, Montreal, Quebec, Canada. ³Sainte-Justine's Research Center, Marie-Enfant Rehabilitation Center, Montreal, Quebec, Canada. ⁴Sainte-Justine Research Center, Marie-Enfant rehabilitation center, Montreal, Quebec, Canada. ⁵Université du Québec à Montréal, Montreal, Quebec, Canada



Melissa Martel

Short Bio of all Presenting Authors

Melissa Martel is an experienced physiotherapist at the Marie Enfant Rehabilitation Center of Sainte-Justine's Hospital in Montreal, Canada. She has been working with children who have neuromuscular diseases for the past 12 years. She did several research projects regarding adapted dancing in children with neuromuscular diseases and cerebral palsy for which she has won two awards. She developped a new method for foot orthoses conception in children with Charcot-Marie-Tooth and started a pilot project to evaluate the impact of this new method. She is currently doing her doctorate in rehabilitation sciences to continue investigating the impact of those new foot orthoses on gait in children with Charcot-Marie-Tooth.

Abstract

Introduction

Charcot-Marie-Tooth is a rare and progressive disease resulting in distal sensory deficit and muscular weakness.^{1–3} As the disease progresses, these deficits result in cavovarus foot deformities in more than 60% of adolescents with Charcot-Marie-Tooth.⁴ The cavovarus foot is a complex and multiplanar foot deformity5,6 characterised by an excessively high longitudinal arch and, to some degree, a varus hindfoot, an adducted forefoot, a plantar flexed first ray, clawed toes,^{3,5} and an ankle equinus.^{3,6} These deformities reduce the ground contact surface and concentrate pressure on the fewer loaded structures, i.e. the forefoot and lateral border of the foot.^{7–9} The cavovarus foot also tends to become more severe and rigid with time^{6,7} and was highlighted as a source of walking and balance difficulties, as well as pain, in people with Charcot-Marie-Tooth.^{1,3,10} Foot orthoses are widely prescribed in this population to support the foot and improve gait,6,11 but there is a lack of guidelines for their conception.³ The common method of FO conception (FOclass) is mostly based on clinical judgment and visual estimation with the intention to correct the observed deformities. The aim of this pilot study was to report a standardized methodology for foot orthosis design (FOmax) based on a clinical foot deformities evaluation in children with Charcot-Marie-Tooth and to assess its effects on gait.

Materials and methods

This study included 11 children with CMT. Participants were provided with a pair of FOclass and a pair of FOmax. For the FOmax design, a full evaluation of the foot deformities was performed and a decision-making algorithm was used with the aim to enhance the distribution of plantar pressure by maximizing the contact surface between the FO and the foot. A 3-D gait analysis and a plantar pressure analysis were performed with both foot orthoses after at a 3-month wear.

Results

A decision-algorithm for FO design is reported. Walking speed, step length and single stance time are increased with FOmax compared to FOclass. Hip flexion/extension range of motion during stance also increased. The pressure-time integral decreased on the lateral midfoot with FOmax.

Discussion and Conclusion

These results suggest that this new method for FO design, offers benefits for walking in children with CMT. The increased step length could be related to the increase of hip range of motion.¹² The increase in walking speed and single support times could result from a better distribution of the plantar pressure that optimizes stability during walking. The reported algorithm helps standardize FO conception, dedicated to children with CMT, in a clinical setting. The objective measurements, needed to specify the FO design, require easily available tools. The reported methodology could be used as a benchmark in FO conception for further studies. It brings forth a standardized methodology for foot deformity correction or compensation, making the process more objective and more customized to the patient's foot. The present results need to be confirmed with a larger sample.

Impact of Ischial Weight Bearing Knee Ankle Foot Orthoses: More than Therapeutic Standing with SMA

Christa Weigel PT, DPT^{1,2}, <u>Laurey Brown PT, DPT¹</u>, <u>Sara Beyler CO/LO¹</u>, Jessica Trenkle PT, DPT^{1,3}, Kristin Krosschell PT, DPT^{1,3}

¹Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, USA. ²M Health Fairview, Woodbury, MN, USA. ³Northwestern University Feinberg School of Medicine Department of Physical Therapy and Human Movement Sciences, Chicago, IL, USA



Laurey Brown



Sara Beyler

Abstract

The physiological and psychological benefits of standing in the neuromuscular population are well documented. Previously, standing opportunities for children with SMA who could not stand independently were limited to static standers. While static standing assists in contracture management and bone density, dynamic standing offers additional benefits of intermittent loading, improved environmental access and peer engagement. With advancement in pharmacologic treatments, notable observed improvements allow for consideration of alternative standing options. To progress participation in dynamic standing, 5 children receiving disease modifying therapy were provided ischial weight-bearing knee ankle foot orthoses (KAFOs) using a collaborative approach between physical therapy (PT) and orthotics.

All five children had confirmed SMA (types 2 and 3) and were hands-free sitters. Their ages at initiation of dynamic standing were 4 to 11 years.

The KAFOs were designed with ischial weight-bearing proximal brims, drop lock knee joints, with either unilateral or bilateral uprights depending on alignment and weight of the patient. Four out of five patients were able to obtain hands-free standing at their initial fitting. The one who did not was the youngest and was limited by apprehension related to a new standing challenge, initially needing upper extremity (UE) support. After two weeks of KAFOs use and support with PT, this patient was also able to stand without UE support.

With regular PT intervention, practice with home programming, and close monitoring by orthotics for fine-tuning of the braces and appropriate fit and alignment, all five individuals were able to progress to supported ambulation with a reverse walker for short distances, with documented gradual improvements in speed, endurance, and efficiency of ambulation over time per 10 Meter and 2 Minute Walk Tests. No adverse effects were reported.

In addition to improved dynamic standing abilities, these individuals and their families were able to verbalize and share photos and videos to document improved participation in social and peer engagement in a variety of environments demonstrating a presumed positive impact on their quality of life. These meaningful moments included standing next to peers for the first time at a birthday party, standing to play basketball in their backyard with a sibling, doing the 'floss dance', and standing outside at the playground, at the library or at an easel to paint.

The use of ischial weight-bearing KAFOs can be a successful intervention to progress dynamic standing participation in individuals with SMA who are hands-free sitters. Participation in dynamic, hands-free standing and short-distance ambulation in KAFOs provides not only a motivating new means of meeting exercise recommendations per the SMA standard of care, but also a new opportunity for engagement in recreational and meaningful activities with peers in a standing position. This opportunity creates a positive effect on engagement and subsequently enhances the individual's quality of life.

Join the Movement: Learn how you can change children's lives by donating equipment through Penta

Anna Szczepanek MS Global Affairs, Mijamin Strong Master's in Global Management

Penta Medical Recycling, New York, NY, USA



Anna Szczepanek

Short Bio of all Presenting Authors

Anna Szczepanek is the Executive Director for Penta Medical Recycling. As Executive Director, Anna leads the strategic growth of the organization, helps to form global and domestic partnerships, and works to achieve Penta's mission of providing mobility around the world. Anna has over 10 years of experience in nonprofit leadership and global health, having worked extensively to develop and execute programs involving access to healthcare services in underserved communities around the world.



Mijamin Strong

Short Bio of all Presenting Authors

Mija was born overseas, growing up and living in Bangladesh, Ethiopia, Kenya & Uganda before moving to the U.S. for university. He has a Bachelor's degree in Construction Management and a Master's in Global Management from the Thunderbird School of Global Management, as well as 4 years of construction management and business consulting experience. Mija is applying this experience in his role as Penta's Director of Operations, providing oversight & direction of Penta's warehouse inventory and supply chain operations.

Abstract

Penta Medical Recycling was founded by university students in 2016 to bring high-quality, low-cost prosthetic care to low-and middle-income countries (LMIC) while repurposing what would otherwise be considered medical waste in the United States. We need your help for our solution to reach more children.

Penta's system came out of the realization that 85-95% of the world's 100 million amputees lack access to proper prosthetic care and equipment. For someone living in LMIC, prosthetic care and components cost years worth of savings, and the cost of a bus ticket to the nearest healthcare facility alone can often be the first barrier to care. In many cases, these facilities will not have trained P&O specialists or the right equipment on hand. In some of Penta's countries of operation, there is only one single P&O center to provide care to the entire country's amputee and limb-difference population. In all of our countries of operation, there is only a fraction of the required number of prosthetists for the number of amputees, and even fewer are trained in pediatric care.

At the same time, upwards of 300,000 prosthetic limbs—many of them perfectly functional—are replaced and discarded in the United States every year. These limbs are typically replaced every 3-5 years while being built to last 8, and cannot be resold due to various regulations, even if they have only been used for a day. As a result, there are millions of prosthetic components collecting dust in amputees' homes, clinic back offices, manufacturer "boneyards," and landfills across the U.S. that could otherwise be changing lives.

Penta has built a system to connect these two issues of waste and need. We collect used, discarded, and unsold P&O equipment from these many sources across the United States, and send them to partner clinics and organizations that provide prosthetic care across 21 different countries. These partners, which include US-based organizations, foreign government health groups, and major hospitals and universities, request the specific equipment they need and distribute it to their patients. Through this system, Penta is able to clear the clutter out of private homes, relieve clinics of the responsibility of collecting unusable devices, and help manufacturers unload excess stock, all while bringing the ability to walk, work, and live to the fullest back to amputees around the globe.

Penta's mission extends to several particularly vulnerable members of the global amputee community, including children, and we want to help more of them. Since the start of 2023, Penta has been making a targeted effort to collect and distribute pediatric equipment so that children can represent 20% of our annual beneficiaries by 2025. We are forging new partnerships with organizations, funders, and industry partners to help get child amputees the equipment they need, and invite you to become partners in our mobility-restoring work. Come to our talk to learn more about how you can be part of the movement!

Children With Fibular and Femoral Deficiency Demonstrate Sex and Racial Variations: A Multi-Center Analysis

Grace Markowski BS¹, Janet L. Walker MD^{1,2}, Hank White PT, PhD¹, Donna Oeffinger PhD¹

¹Shriners Children's, Lexington, KY, USA. ²University of Kentucky Department of Orthopaedic Surgery and Sports Medicine, Lexington, KY, USA

Abstract

Introduction

Male sex predominance in fibular deficiency is well documented.1-3 Femoral and fibular deficiency are thought to represent a spectrum of the same embryological defect.4 Lower-limb amputation is common treatment for severe forms of femoral and fibular deficiency. Sex and race disparities have been reported in adult lower-limb amputations but not pediatrics.5-9 We hypothesized there are sex and racial differences in severity and amputation rates in children with femoral and fibular deficiency.

Methods

A retrospective review was performed of 1825 children with femoral and fibular deficiency, treated at 7 pediatric orthopaedic centers, comparing sex, race, diagnosis, laterality, number of foot rays, and associated hand anomalies. Diagnosis was based on the limb segment with greatest %shortening. It is accepted that most patients with femoral or fibular deficiency also have mild deficiencies in the other limb segment. Patients with femoral deficiency and complete fibular deficiency were placed in an intermediate group for the spectrum, having substantial deficiency in both segments. Representing our largest, most consistent group, we selected a subset of 565 children with unilateral fibular deficiency, who were ≥5 years old and living in the continental US, to assess differences of sex and race on amputation rates, relative to severity. Where available, severity of fibular deficiency was classified using Achterman+Kalamchi (A+K Type I vs II) and Birch (Type 1A+1B vs 1C,1D,2A) systems. Variables were compared using Chi square analysis. Significance was accepted at p<0.05 with Bonferroni correction.

Results

Data is reported in Table 1. There were 1002 males and 823 females. The patient-reported race/ethnicity distribution was 1018 White, 434 Hispanic, 225 Black, 71 Asian, and 77 other. There was no significant relationship between sex and race. The distribution of males across the femoral and fibular deficiency spectrum was more shifted to the fibular end and females were more evenly distributed. All racial groups had more fibular than femoral deficiency, except those reporting Black

race. There was no sex or race/ethnicity relationship with laterality, hand anomalies, or missing foot rays.

Amputation for unilateral fibular deficiency did not differ with assigned sex at birth. The rate of amputation was lowest for those reporting Hispanic ethnicity. The highest rate was for those reporting Asian race. This racial difference was true regardless of the severity of fibular deficiency.

Conclusions

Sex and racial differences in femoral and fibular deficiency exist in pediatric patients. Femoral and fibular deficiency is overall more common in males, shifted toward the fibular end of the spectrum. Femoral vs. fibular deficiency was more evenly distributed within females. Fibular deficiency is more common than femoral deficiency for all race/ethnicity groups except those reporting Black race. Amputation rate in unilateral fibular deficiency was lowest for those reporting Hispanic ethnicity and highest for those reporting Asian race.

These sex and race variations within the femoral and fibular deficiency spectrum have implications when studying its embryology. Cultural differences may exist for patient choice or physician preference of amputation in fibular deficiency. Other factors contributing to treatment choices should be further examined.

Table 1	Entire	Distribution Across the Femoral-Fibular Deficiency Spectrum			Amputation Rates: Unilateral Fibular Deficiency		
	Cohort N=1825	Femoral N=673	Femoral + A+K II N=193	Fibular N=959	A+K I n=319	A+K II N=180	Birch 1A+1B N=341
Female	823 (45%)	344 (41.8%)*	101 (12.3%)	378(45.9%)*	11/125 (8.8%)	52/82 (62.2%)	14/129 (10.9%)
Male	1002 (55%)	329 (32.8%)*	92 (9.2%)	581(58.0%)*	21/194 (10.8%)	72/98 (73.5%)	28/212 (13.0%)
Asian	71 (3.9%)	14 (19.7%)	15 (21.1%)	42 (59.2%)	3/10 (30.0%)*	16/18 (88.9%)*	4/11 (36.4%)*
Black	225 (12.3%)	120 (53.3)%*	38 (16.9%)	67 (29.8%)*	2/22 (9.1%)	9/17 (52.9%)	1/21 (4.8%)
Hispanic	434 (23.8%)	180 (41.5)%	39 (9%)	215 (49.5%)	2/63 (3.2%)*	11/25 (44.0%)*	1/66 (1.5%)*
White	1018 (55.8%)	326 (32.0%)*	94 (9.2%)	598 (58.7%)*	25/216 (11.6%)	82/115 (71.3)%	35/235 (14.9%)
Other	77 (4.2%)	33 (42.8%)	7 (9.0%)	37 (48.1%)	0/8 (0%)	5/5 (100%)	1/8 (12.5%)

A+K = Achtermann and Kalamchi classification for fibular deficiency

* statistical significance p<0.05 with Bonferroni correction

The Presence of Kyphosis in Individuals with SMA treated with Zolgensma

Laurey Brown PT, DPT¹, Sara Beyler CO/LO¹, Christa Weigel PT, DPT^{2,1}, Katie Hoffman PT, DPT¹, Kristin Krosschell PT, DPT^{1,3}

¹Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, USA. ²M Health Fairview, Woodbury, MN, USA. ³Northwestern University Feinberg School of Medicine Department of Physical Therapy and Human Movement Sciences, Chicago, IL, USA



Laurey Brown



Sara Beyler

Abstract

Treatment of Spinal Muscular Atrophy (SMA) has seen significant advancements in recent years including the advent of three commercial drugs which have revolutionized the outcomes for this diagnosis. Prior to treatment availability, individuals with the most severe types of SMA would typically not live past 2 years of age and would not achieve functional sitting. Now, these same individuals are surviving and can demonstrate functional skills that are similar to their same aged peers. Although there have been considerable advancements, it is important to understand that there continue to be functional impairments and qualitative concerns.

One such trend that has been observed is the development and progression of a thoracic kyphosis that can become rigid over time. For 23 patients who were treated at a single-center with Zolgensma, this trend was observed either via x-ray or visual observation in 10 accounts.

Previously it was accepted that individuals with SMA presented with significant decrease in spinal extensor strength and, as a result, had difficulty clearing the head in prone or maintaining upright sitting. It was also suggested that the muscles responsible for flexion movements were more dominant than those responsible for extension movements. This was similarly observed by the development of elbow and knee contractures over time.

With treatment there have been significant muscle strength and functional gains observed though it appears that spinal extensor weakness may continue to be a relative concern. Thus, while these individuals are more readily tolerant to upright positions, they continue to lack the spinal extensor strength to perform sitting in an aligned and erect position and often assume a functional, kyphotic position that can become rigid over time.

There are multiple strategies to assist in managing and monitoring this kyphosis concern. First, it is recommended that spinal x-rays of the thoracic spine should be conducted in accordance with routine Orthopedic visits. When possible, a sagittal image should be acquired for documentation and on-going assessment of the prevalence of this concern. Second, when appropriate, the use of pre-emptive orthoses should be considered to promote proper alignment as the individual continues to gain strength and work toward more independent upright control. Finally, the therapeutic use of prone positioning should be an essential component to an individual's daily plan of care. Regardless of the level of independence, a person should be placed prone to assist in balancing gravitational forces placed on the spine during development to maintain overall efficiency in alignment.

As clinicians working alongside individuals with SMA in this new era of treatment, it is clear ongoing challenges remain when it comes to postural alignment and strength. We are tasked to anticipate underlying spinal weakness that impacts the acquisition of balanced and symmetrical postural alignment. The qualitative components of alignment should not be overlooked while one works towards opportunities to acquire functional gains and independence. Enhanced awareness and implementation of known treatment strategies to manage kyphosis have the potential to contribute to better outcomes leading to improved function and efficiency while executing activities of daily life.

Tibial Deformities and Physeal Injuries with Distal Femoral Expandable Endoprosthesis Implants

Dr. TJ Utset-Ward M.D., Daryn Strub BA, CRC, Dr. Thomas Scharschmidt M.D.

Nationwide Children's Hospital, Columbus, Ohio, USA



Dr. TJ Utset-Ward

Short Bio of all Presenting Authors

TJ Utset-Ward is an orthopedic oncologist with a particular interest in pediatric sarcoma. He completed a Musculoskeletal Oncology surgical fellowship at The Ohio State University and continued additional pediatric-specific training at Nationwide Children's Hospital as a Pediatric Orthopedic Oncology Fellow. He previously completed residency at the University of Chicago, medical school at Vanderbilt University, research fellowship at Moffitt Cancer center and Master of Business Administration at Vanderbilt University. His interests include osteosarcoma and osteosarcomagenesis, exosomes, clinical outcomes studies, and translational innovations such as 3D printing for oncologic applications. He is interested in maximizing the lives and function of children undergoing limb salvage and amputations for trauma and cancer.



Daryn Strub

Short Bio of all Presenting Authors

Daryn is a Clinical Research Coordinator at Nationwide Children's Hospital. He specializes in pediatric orthopedic surgery research and pediatric orthopedic oncology research. He completed his bachelor's degree in Biological Sciences at Miami University. His medical interests include osteosarcoma, total hip arthroplasty, degenerative hip diseases, lower extremity amputation, and sports medicine.



Dr. Thomas Scharschmidt

Short Bio of all Presenting Authors

Thomas Scharschmidt is the director of the Pediatric Orthopedic Oncology Program at Nationwide Children's Hospital and a Professor in Orthopaedics at The Ohio State University Medical Center and James Cancer Hospital. His clinical interests include bone and soft tissue sarcomas in adults and children, benign bone and soft tissue tumors in adults and children, complex limb reconstruction, advanced reconstruction options in the growing child, care of the oncologic amputee patient and spine tumors.

Abstract

Introduction: Expandable distal femoral replacement (eDFR) implants can progressively reduce leg length discrepancies and accommodate for growth in skeletally immature patients undergoing femoral physis sacrificing oncologic resections. In our use of the Juvenile Tumor System (JTS), we have noticed acquired proximal tibial deformities. Studies have demonstrated disruptions in tibial growth following implantation, but none has investigated the exact physeal disruption. We aim to investigate if the location of the tibial stem entry in the physis, patient growth, implant design and parameters or other factors will predict the development of the characteristic proximal tibia deformities. To better study this, we also aim to establish recommendations and guidelines for radiographic follow-up of lengthening.

<u>Methods</u>: A total of 16 patients receiving a JTS distal femoral replacement for oncologic indication from 2014-2023 were included. We retrospectively reviewed preoperative and post-operative imaging to measure stem placement in the physis, alignment of the proximal tibia, and limb discrepancies. We will use CTs and pre-operative image analysis with 3D modeling of the custom prostheses to map the tibial stem footprint to a novel gridded map of the proximal tibial physis currently under development.

<u>Results:</u> A proximal tibial deformity of greater than 5 degrees was noted in 7 of the 16 (44%) cases. Proximal tibial deformities with respect to the component ranges from 0-11.5 degrees and always in a varus pattern. However, in most cases deformity did not affect overall limb alignment and only 1 case had mechanical axis deviation greater than 1cm. We found a statistically significant correlation between overall patient growth and development of proximal tibia varus changes (R 0.51, p=0.042). Larger stem diameters did not predict development of deformity. We are currently analyzing the exact location of physeal entry of the stem and stresses at implantation.

Conclusions: With the current JTS eDFR implant design, the area of the proximal physis that is injured is determined by an implant stem position dictated by the intramedullary canal of the tibia. Variability in stem size and patient growth potential may further dictate the development of the deformity. Further studies with multi-institutional collaboration with standardized radiographic monitoring are needed to better understand the incidence of this deformity and contributing factors of implant design and patient anatomy.

Significance: Expandable endoprosthesis implants have extended more long-term limb-salvage options for the growing pediatric population. Although the technology the expand the prostheses, which can now often be done non-invasively, has advances, there are additional challenges with the growing skeleton that need to be addressed when placing large implants. Understanding what factors in implant design and positioning contribute to the development of deformity may shape future practice and implant design as application of these growing implants expands.

A Rehab Perspective on the Impact of Scoliosis and Function for Individuals with Spinal Muscular Atrophy

Sara Beyler CO/LO¹, Laurey Brown PT, DPT¹, Katie Hoffman PT, DPT², Christa Weigel PT, DPT³, Kristin Krosschell PT, DPT^{1,4}

¹Ann & Robert H. Lurie Childrens Hospital of Chicago, Chicago, IL, USA. ²Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, USA. ³M Health Fairview, Woodbury, MN, USA. ⁴Northwestern University Feinberg School of Medicine Department of Physical Therapy and Human Movement Sciences, Chicago, IL, USA



Sara Beyler



Laurey Brown

Abstract

Spinal Muscular Atrophy (SMA) is characterized by progressive and systemic neuromuscular weakness. As the disease progresses, the presence of scoliosis is well documented with typical demonstration of rapid and early curve progression and subsequent decrease in vital capacity. Curve severity is variable and is typically associated with an individual's functional level as classified by sitters, non-sitters and walkers. Sitters typically have higher degree curves followed by non-sitters and finally, walkers with all groups demonstrating a presence of scoliosis to some extent. As pharmacologic advancements occur, the phenotype for the natural history of individuals with SMA is evolving. However, even with life-changing advancements, the development of significant spinal curvature continues to be a concern, requiring multidisciplinary management. Additionally, while the negative impact of scoliosis development on function is broadly accepted, little literature describes specific functional impact as it relates to curve progression.

These individuals are followed by Orthopedists and often involve orthotic management as one strategy for addressing scoliotic curves, with differing techniques available. Despite strong evidence that orthotic management does not change the natural history of neuromuscular scoliosis curve progression, these devices are routinely recommended to provide upright support and to presumably assist in improving upper limb functional performance. Different orthotic management strategies include both soft and thermoplastic braces as well as varying features within the thermoplastic brace category. Modifications are typically made to address the individual's respiratory function and accommodate any breathing compensations while using an orthosis. Bracing recommendations are highly variable with little standardization for best practice.

Physical therapists can administer standardized, criterion-referenced scales, such as the Hammersmith Functional Motor Scale - Expanded (HFMS-E) and the Revised Upper Limb Module (RULM), that are sensitive to change and designed to quantify functional abilities in individuals with SMA. These tests reflect necessary skills for engaging in real-world activities and help potentially further understand the impact of scoliosis progression on function.

This case series demonstrates the evolving natural history of scoliosis progression in four individuals with SMA (ages 8-15), all treated with Spinraza with a functional level of sitting. Their curve progression and functional changes with age and growth will be outlined. Two received posterior spinal fusions and two utilize thermoplastic bracing. For the individuals with higher curve magnitude and greater functional involvement, there is a demonstrated discrepancy in sides when performing RULM testing. Additionally, it is observed that functional performance can deteriorate initially after a posterior spinal fusion. This necessitates the importance of obtaining therapeutic intervention as soon as medically cleared to do so, while adhering to postoperative spinal precautions.

If the link between scoliosis and functional performance is more widely understood, the impact of curve development will be better interpreted. This could improve patient interest and compliance for spinal orthoses in the interest of the possible functional gains with supported sitting alignment. With multi-disciplinary care, including orthopedic assessments addressing these entities, clinicians will be more informed and better able to approach the on-going concerns for spinal management in this population.

Challenging Case:

Dr TJ Utset-Ward M.D.¹, Dr. Michael Eckhoff M.D.^{1,2}, Dr. Thomas Scharschmidt M.D.¹

¹Nationwide Children's Hospital, Columbus, Ohio, USA. ²The Ohio State University - Wexner Medical Center, Columbus, Ohio, USA



Dr TJ Utset-Ward

Short Bio of all Presenting Authors

TJ Utset-Ward is an orthopedic oncologist with a particular interest in pediatric sarcoma. He completed a Musculoskeletal Oncology surgical fellowship at The Ohio State University and continued additional pediatric-specific training at Nationwide Children's Hospital as a Pediatric Orthopedic Oncology Fellow. He previously completed residency at the University of Chicago, medical school at Vanderbilt University, research fellowship at Moffitt Cancer center and Master of Business Administration at Vanderbilt University. His interests include osteosarcoma and osteosarcomagenesis, exosomes, clinical outcomes studies, and translational innovations such as 3D printing for oncologic applications. He is interested in maximizing the lives and function of children undergoing limb salvage and amputations for trauma and cancer.



Dr. Michael Eckhoff

Short Bio of all Presenting Authors

Michael Eckhoff is the Musculoskeletal Oncology fellow at Ohio State University. His orthopedic training was in El Paso, Texas through Texas Tech University Health Sciences Center El Paso, and his medical degree was earned at the Uniformed Services University in Bethesda, Maryland. His research interests are in limb preservation surgery, amputee care, and osseous integration.



Dr. Thomas Scharschmidt

Short Bio of all Presenting Authors

Thomas Scharschmidt is the director of the Pediatric Orthopedic Oncology Program at Nationwide Children's Hospital and a Professor in Orthopaedics at The Ohio State University Medical Center and James Cancer Hospital. His clinical interests include bone and soft tissue sarcomas in adults and children, benign bone and soft tissue tumors in adults and children, complex limb reconstruction, advanced reconstruction options in the growing child, care of the oncologic amputee patient and spine tumors.

Abstract

The Problem:

We present the case of a 16-year-old male with severe arthrogryposis and multiple joint contractures who have been unable to ambulate and has had to remain prone in a rolling-bed, modified wheelchair for transport and activity. Arthrogryposis multiplex congenita is a non-progressive disorder characterized by multi-joint contractures with secondary bone deformities. Joint involvement can significantly affect a patient's quality of life and function. Our patient has significant involvement of his hips and elbows, and concomitant scoliosis. He has spent his life in a prone position propped up on his elbows due to severe and rigid hup extension contractures. He has been unable to assume a seated position. Prior to presentation, he had undergone bilateral through-knee amputations due to knee flexion contractures and clubfeet. He presented to clinic and appealed to us to find a way to let him sit and look out and potentially stand.

Prior attempts to increase his hip range of motion through soft tissue releases, hip extensor lengthening and capsular releases, were not successful. His case is further complicated by a dislocated and proximally migrated right hip, and femoral shafts of 8mm diameter. Because he has spent years prone, unable to ambulate or sit, his bones have also experienced little load and are severely weakened to the point of being soft and pliable. The long-term goal of this patient is to be able to ambulate with the use of prosthetics, with a short-term goal of attaining a seated position for the first time in his life.

The Solution:

We wish to present this case for discussion as we have considered and discussed multiple options with the patient and his family including total hip arthroplasty with custom acetabular and proximal femoral replacement components. Ultimately for this patient, we planned on a staged procedure with circumferential soft tissue releases and resection arthroplasty, followed by later proximal femoral replacement with custom implants designed to accommodate his small femur sizes. Intraoperatively at the time of the resection arthroplasty, his bone quality was found to be severely osteopenic, and it was determined that he likely would not be reconstructable with endoprosthetic implants. We performed soft tissue releases with femoral shortening and resection arthroplasty to regain hip range of motion. We created a a soft tissue restraint with bone-to-bone suturing to re-align his femoral shafts with the acetabula, achieving 90 degrees of hip flexion so he could be seated. We positioned the proximal residual femur within the acetabula to prevent migration. A spica cast was applied postoperatively to hold his flexed position while his soft tissues healed.

Addressing Ableism: Assumptions, Advocacy, and Accessibility

Addressing Ableism: Assumptions, Advocacy, and Accessibility Gabrielle Nguyen MD, Addressing Ableism: Assumptions, Advocacy, and Accessibility Marina Ma MD, Addressing Ableism: Assumptions, Advocacy, and Accessibility Stephanie Miller DO

Texas Children's Hospital, Houston, TX, USA



Addressing Ableism: Assumptions, Advocacy, and Accessibility Gabrielle Nguyen



Addressing Ableism: Assumptions, Advocacy, and Accessibility Marina Ma



Addressing Ableism: Assumptions, Advocacy, and Accessibility Stephanie Miller

Abstract

Ableism is a form of discrimination or prejudice that involves the marginalization, stigmatization, or devaluation of individuals or groups based on their perceived abilities or disabilities. As providers that work in rehabilitation we feel that is important that we understand its definition and proposed causes, as well as address the pervasiveness of these views in the healthcare system and our daily lives.

This presentation hopes to not only address the meaning and manifestations of ableism, but also to consider other factors that can be oppressive to these individuals.

For example intersectionality- the complexities of the cumulative ways that multiple forms of discrimination (such as racism, classism, sexism, homophobia) can combine/ overlap/ or intersect in the experiences of these marginalized or minority groups.

The healthcare system- how do we discriminate subconsciously against our patients? Do we use microaggressions and ablelist language to perpetuate preconceived notions about their intelligence and their needs? Further how do we address learners within our training systems with disabilities? Do we adequately accommodate their needs and do we have realistic expectations of their performance?

While we realize that these topics and discussions can be triggering or uncomfortable, the goal of this presentation is a call to action- to be an ally/ accomplice for our patients, and to recognize, credit, and compensate disabled people.

Approach to Vascular Anomalies: An Introduction to Classification and Case Report

Dr Gabrielle Nguyen MD, Dr Stephanie Miller DO, Dr Nicole Montgomery MD

Texas Children's Hospital, Houston, TX, USA



Dr Gabrielle Nguyen



Dr Stephanie Miller



Dr Nicole Montgomery

Abstract

Vascular anomalies involving the extremities often present to rehabilitation or orthopedic clinicians in a variety of ways, including but not limited to: discoloration, masses, overgrowth, limb length difference, extremity or joint pain. The aim of this review is to familiarize providers with the different types, syndromes, and classifications, and use a case study to demonstrate the role of the rehabilitation or orthopedic clinician in treating and managing vascular anomalies.

1. Briefly vascular anomalies can be divided into the following:

- Capillary Malformations, lymphatic Malformations, venous Malformations, AVM's, Combined Malformations

- 2. Associated Clinical Syndromes with Vascular anomalies
- Klippel Trenaunay Syndrome (KTS), Parkes Weber, Servelle-Martorelle, Maffucci, CLOVES, Proteus
- 3. Tumors
- Benign, locally aggressive, malignant
- 4. Unclassified Anomalies

- Intramuscular Hemangiomas, PTEN hamartomas of soft tissue (PHOST), Fibroadipose Vascular Anomaly (FAVA)

Summary of Classification: The above classification is a system developed by ISSVA to categorize and differentiate vascular anomalies based on their vessel composition and syndromes. Many of these anomalies directly affect the musculoskeletal system, so familiarity with their diagnoses can help clinicians manage, recognize, and diagnose these conditions.

Case Study:

18 y.o. female, with congenital mosaic overgrowth disorder (CLOVES Syndrome) caused by a somatic mutation in PIK3CA. She is s/p right foot amputation and multiple other orthopedic surgeries, with h/o Nephroblastomatosis diagnosed 7/31/07. She has had the following previous interventions: R Syme Amputation

She is undergoing treatment for CLOVES with Miransertib and is undergoing surgical debulking with PRS. She has had lipectomy and most recently had debulking surgically on 1/26/23.

She utilizes a R foot AFO or prosthesis and is a community ambulator that is independent for ADL's. She recently had more success with a prosthesis but it no longer fits after her last debulking. Could consider additional debulking in next few months, but states she does not want to have more surgery in the near future.

Discussion:

These patients require multi disciplinary care due to their constantly changing orthotic and prosthetic designs with volume fluctuations and changes in distal limb girth. Multiple conversations are required to decide whether to adapt to their current anatomy, or whether surgery is needed to once conservative management is optimized. These diseases are often progressive, so the aggressive nature and the difficulty with fit requires many nuanced discussions with care providers of all areas.

Having Difficult Conversations: Updates and Outcomes from 2023

<u>Dr Stephanie Miller DO</u>, Dr Dorothy Beauvais MD, <u>Ms Brittni Wills DPT</u>, Dr Gabrielle Nguyen MD Texas Children's Hospital, Houston, TX, USA



Dr Stephanie Miller



Dr Dorothy Beauvais



Ms Brittni Wills



Dr Gabrielle Nguyen

Abstract

This presentation is intended to be a follow up to our talk last year on difficult discussions. Last year we introduced different ways to approach conversations on sensitive subjects, most significantly the discussion of amputation vs limb salvage.

This year we would like to follow up this talk with a case series of 3 patients that benefitted from these conversations- one of which received an amputation, one who is planning for an amputation, and one who is still in the stages of contemplation- and describe what we have learned from these experiences and how to continue to progress care for these patients in the future.

Our goal is to make this discussion multi disciplinary, with the point of views of a rehab physician, orthopedic surgeon, and physical therapist, on how we each bring different perspectives to the conversation, and also to invite others to share their experiences as well.

Hands-on upper extremity prosthetic training based on developmental skill progression, part 2.

Mary Ellen Brown MS, OTR/L

Shriners Children's-New England, Springfield, MA, USA



Mary Ellen Brown

Short Bio of all Presenting Authors

Mary Ellen Brown has been a pediatric Occupational Therapist at Shriners Children's-New England for over 30 years, gaining expertise in prosthetic training, pediatric hand therapy, as well as treating children with neuromuscular and orthopedic conditions. She has been an adjunct professor as well as provided multiple lectures for local colleges and universities. She has participated in several hand surgery/hand therapy medical trips to Nicaragua through Healthcare Volunteers Overseas (HVO). Prior to OT, she was a Certified Child Life Specialist which provided the psychosocial and developmental basis for her OT career.

Abstract

Prosthetic training for children requires specialized therapeutic interventions from trained therapists (Mano et al., 2020) that is often difficult for families to find. Few resources are available for the pediatric therapist on specific prosthetic training skill development and progression (Huinink et al., 2016), especially as it relates to developmental milestones. We propose a detailed developmental skill progression checklist for voluntary-opening and voluntary-closing, body-powered prostheses that will help new and experienced therapists work with children of all ages to develop age-appropriate prosthetic skills as they journey through prosthetic options. This skill progression is easy to use in any therapy setting and helps to establish appropriate goals for both the new user and the experienced super-user.

In a follow-up to the ACPOC 2023 presentation, this interactive presentation will introduce practitioners to a newly proposed developmental skills checklist for pediatric prosthetic training based on developmental skills progression. Multiple videos of pediatric clients will be utilized to demonstrate specific skills, and participants will be able to practice using the checklist to determine skill level, as well as to determine appropriate goals for specific cases. Prosthesis simulators will be available for hands-on learning (Sinke, etal, 2022

YEP: Empowering Youth Living with Limb Loss or Limb Difference through Peer Engagement

Maurice Henson MA

Amputee Coalition, Washington DC, DC, USA

Maurice Henson

Short Bio of all Presenting Authors

Maurice Henson is the Director of Youth and Workforce Engagement at the Amputee Coalition. Prior to joining the Coalition, Mr. Henson served as Vice President of Operations for the Boys and Girls Clubs of America, Pikes Peak Region.

Abstract

This abstract provides an overview of the Amputee Coalition's Youth Engagement Program, highlighting its objectives, key goals, and impact. The Youth Engagement Program addresses the unique needs, challenges, and equity gap faced by youth in the limb loss and limb difference community.

Amputee Coalition's Youth Engagement Program includes life skills resources, education and training, youth camp, workforce development, and mentorship inclusive to all youth. Under the YEP program lives our Youth Engagement Workforce Development program which understands the disparities and social determinants of health and well-being, mental health, and systematic inequality that youth face specifically in the Black community and we see continued opportunity to be a vital pipeline to invest in our youth's educational journey and outlook, employment progression through our intentional programming and resources for our youth participants.

Our vision is to expand our reach to African American/Black, Hispanic/Latino, Asian, Pacific Islanders, and LGBTQ youth and teens living with limb loss or limb difference by developing a technology platform to share life skills and training programs, providing mentorship, and a career dashboard for summer job opportunities.

The Amputee Coalition Youth Engagement Program aims to create a supportive and inclusive community for youth in the limb loss and limb difference community, fostering a sense of belonging and empowerment. Through a combination of educational resources, mentorship opportunities, and interactive events, YEP seeks to enhance our youth participant's resilience and self-confidence while promoting active engagement in various aspects of their lives.

Central to the program is the concept of mentorship, where those with lived experience serve as role models and provide guidance to our youth participants. The Youth Engagement Program's online platform serves as a hub for information and resource specific to youth development, youth workforce development, peer-to-peer connection, and creating a youth lead dialogue rooted in advocacy, social & emotional well-being, entrepreneurial efforts, civic engagement, the adoption of a healthy lifestyle, and career and educational exploration.

With a focus on impacting and addressing challenges faced by youth in the limb loss & limb difference community, the Amputee Coalition's Youth Engagement Program strives to contribute to improved mental health outcomes and increased participation in social, educational, and vocational pursuits, the program's emphasis on empowerment, resilience building, and peer support positions the Amputee Coalition's Youth Engagement Program as a valuable resource to youth navigating limb loss and limb difference during formative years. As a result, YEP is making a meaningful and lasting impact on the lives of the youth we serve in the limb loss and limb difference community.

Bone Anchored Limb Prosthesis for Complex Congenital Focal Femoral Deficiency: A Case Report

Aaron B. Epperson MS, Mohamed E. Awad MD MBA, Jason W. Stoneback MD

Department of Orthopedics, University of Colorado Anschutz Medical Campus, Aurora, CO, USA



Aaron B. Epperson



Mohamed E. Awad



Jason W. Stoneback

Abstract

Introduction: Bone-anchored limb (BAL) implantation is a surgical technique that anchors a titaniumalloy implant into an amputee's skeletal residuum. A transcutaneous adapter exits through an opening in the skin called a stoma, connecting it to a standard prosthetic limb. Multiple studies corroborate BAL implantation as a superior option for patients unable to tolerate traditional socket-mounted prosthesis (SMP) with improved gait patterns,[1] shortening the length of Timed Up and Go and 6-minute walk tests[2]. Additionally, patients with BALs have osseo-perception of their limb, which increases comfort and gait safety.[3] Patients experience decreased prosthetic fit complications, including less soft tissue irritation and breakdown [4] and greater functional capacity.[5]

Case:

The Problem: A 28 y/o female with congenital focal femoral deficiency associated with a club foot and shortened RLE. After 14 reconstructive procedures, a decision was made to undergo amputation in 2002 following years of limb salvage procedures. The index amputation surgery in 2002 was described as a nonfunctional turn-up v rotationplasty that was poorly amenable to prosthetic devices, as none that were trialed fit adequately; furthermore, her surgery was complicated by infection with S. aureus, leading to renal failure necessitating dialysis for three months. The patient reported that, over the next several years, she experienced severe phantom pain requiring an implantable spinal stimulator up until subsequent revision amputation in 2013. Limb volume fluctuated throughout her teenage years and into early adulthood; she tried twenty traditional SMPs and was dissatisfied, citing poor prosthetic fit, frequent skin irritation, breakdown, infection, and residual limb pain.

The Solution: She ultimately underwent a two-stage right transfemoral BAL implantation in 2022. At 12 months postoperatively, she reported no substantial complications with the exception of two instances of pain and drainage of her BAL stoma, treated empirically with oral antibiotics, after which the symptoms promptly abated. Additionally, she reports rare anterior thigh pain, though primarily related

to periods of increased activity. Despite these occasional symptoms, her reported quality of life and functional ability are much better than with socket-mounted prostheses. Her stated goals in pursuing BAL implantation were to no longer suffer the skin breakdown she experienced with prior prostheses and to return to her favorite activities, hiking and biking. Her goals have been met, and she is very pleased with her decision to undergo this intervention at 12 months postoperatively. This patient is a model patient for BAL implantation, as she diligently maintains her stoma with twice-daily cleaning and refrains from high-impact activities.

When asked if she would consider BAL again, the patient replied, "Yes, definitely! Even with pain, it is way more comfortable. I do not dread putting my leg on in the morning."

Conclusion: This patient reports that she is functionally better than when using traditional SMPs. Her quality of life and activity level exceed most patients with unilateral femoral socket prostheses. BAL implantation is a reasonable choice for carefully selected patients.

Determining outpatient PT frequency and insurance limitations with pediatric prosthetic training

Brittany Guidry DPT, Sharon Malek DPT, Kelly Phelan DPT, Brittni Willis DPT

Texas Children's Hospital, Houston, TX, USA

Brittany Guidry

Short Bio of all Presenting Authors

Brittany, Sharon, Kelly and Brittni are Physical Therapists at Texas Children's Hospital and work in PM&R's Limb Difference Clinic and treat pediatric patients in the Outpatient setting with limb difference and limb loss.

Abstract

There are varieties of factors to consider when deciding and recommending the amount & frequency of outpatient pediatric physical therapy sessions when creating a plan of care for a pediatric patient with limb loss. We review pediatric outpatient guidelines, recommendations, and considerations as well as examples of frequency of PT sessions used in the adult population with limb loss. We will give patient specific cases/examples using this information to decide on the patient's outpatient PT frequency and or if another setting is recommended such as inpatient rehab. We also will discuss limitations with insurance approval for outpatient pediatric prosthetic training and recommendations to justify recommended frequency.

Effect of the Ponseti Technique on the Contralateral Foot: A Longitudinal Study

Kelly Jeans MS¹, Victoria Blackwood MS¹, Anthony Riccio MD^{1,2}

¹Scottish Rite for Children, Dallas, Texas, USA. ²UTSW, Dallas, Texas, USA



Kelly Jeans

Short Bio of all Presenting Authors

Kelly Jeans earned her Bachelor of Science degree from the University of Southern California in Exercise Science and her Masters of Science degree from California State University, Long Beach. After finishing her Master's Thesis, A Kinematic Analysis of Deep Water Running in Arthritic Individuals, she joined Scottish Rite for Children in 2001, to continue her passion for research. Over the last 20+ years, she has collaborated with researchers interdepartmentally, including orthopedics, orthotics and prosthetics, therapy services and with outside organizations. Her career has focused on the study of movement patterns and cardiovascular fitness in clinical populations including clubfoot, lower extremity amputation, cerebral palsy, adolescent idiopathic scoliosis and early onset scoliosis. She is currently the Division Director of the Movement Science Lab in Dallas. She is a member of the Gait and Clinical Movement Analysis Society and the Association of Children's Prosthetic-Orthotic Clinics, where she serves on the board of directors.

Abstract

INTRODUCTION

Idiopathic clubfeet (CF) can be successfully treated using non-operative methods. Good clinical outcomes1 have led our institution to pursue non-operative treatments including the Ponseti2 technique and the French Physiotherapy (PT) method3. The Ponseti technique includes correction through serial casting followed by a maintenance phase, where the child is fit with a foot abduction

brace. In unilateral patients, since the brace is applied to both feet (CF and unaffected), the contralateral side is inadvertently "treated". The PT method obtains correction through stretching and taping, and is followed by a maintenance phase of splinting, which is only applied to the CF side, leaving the contralateral side untreated. The purpose of this study was to determine if there are pedobarographic differences found in the unaffected foot in unilateral CF patients treated with the Ponseti abduction brace, and if those differences persist over time.

CLINICAL SIGNIFICANCE

In patients with CF, the Ponseti method requires the unaffected foot to be placed in the abduction brace during the maintenance phase of treatment (external rotation and dorsiflexion). This requirement may inadvertently effect the unaffected foot and how it develops over time.

METHODS

A retrospective review was conducted from an IRB approved prospective clubfoot registry from 2001-2023. A total of 44 patients with unilateral clubfoot initially treated non-operatively (Ponseti or PT) were followed longitudinally at 2, 5, 10, and 16 years of age. There were 19 patients treated with the Ponseti technique and 25 patients treated with the PT method. Pedobarograph data were collected at each visit. Analysis included segmenting the foot into the medial and lateral hindfoot and midfoot, along with the forefoot separated into the 1st, 2nd, and 3rd-5th metatarsals. Normalized plantar pressure variables included contact area (CA%; percent of the total foot), mean force (MF%; percent of body weight), contact time (CT%; percent of the roll over process). Non-parametric Mann Whitney U tests were used to determine differences between groups (p set to 0.05).

RESULTS

Table 1 below shows the results for the variables that showed significant differences between the unaffected Ponseti feet and the unaffected PT feet at each of the 4 visits.

DISCUSSION

At 2yrs of age, unilateral clubfoot patients undergoing the Ponseti technique, are still prescribed the brace for nights/naps and/or are just coming out of that phase. At the 2yr research visit, compared to the PT control group, the unaffected-Ponseti foot shows increased force and contact time through the midfoot, indicating treatment effect. By age 5 years, after the brace has been discontinued, no significant differences are found between the unaffected feet. At age 10 years, there was a significant decrease in contact area in the 1st metatarsal in the Ponseti group, but this finding appears to be resolved by age 16 years. The main differences in plantar pressures are seen while the unaffected Ponseti feet are still being "treated" by the brace, but it seems that there is no lasting effect once the bracing phase is discontinued, and by skeletal maturity.

Use of Foot Abduction Orthoses in the Treatment of Clubfoot: An International Survey of Caregivers

Professor Emeritus Thomas Cook PT, PhD, Professor Jose Morcuende MD, PhD

The University of Iowa, Iowa City, Iowa, USA

Professor Emeritus Thomas Cook

Short Bio of all Presenting Authors Professor Emeritus, Physical Therapy and Public Health, The University of Iowa

Professor Jose Morcuende

Short Bio of all Presenting Authors Professor, Orthopedics and Pediatrics, The University of Iowa

Abstract

The purpose of this study was to describe parent/caregiver experiences and issues while using a foot abduction orthosis following correction of their child's clubfoot deformity with the Ponseti method. An internet-based self-administered English language survey was sent out through social media outlets and various parent support websites and was open for 10 days in September 2023. The survey was primarily made up of multiple-choice questions with categorical responses. Simple frequencies were calculated for respondent characteristics and responses to survey questions. The group of 354 children who were reported to be under the age of five were used in the analysis.

Of the shoe/boot choices listed in the survey, 84.8% of respondents indicated that their child was using one of the five commercially available shoes/boots while 10.1% were using Other/Custom or AFO's; 5.1% were not sure. Of the bar choices listed in the survey, 90.9% of respondents indicated that their child was using one of seven commercially available bars while 5.7% were using Other/Custom and 3.4% were not sure.

Almost two-thirds (61.6%) of respondents indicated that they at least mildly agreed that they could afford to purchase their child's current orthosis. Two-thirds (66.1%) rated their child's orthosis as being at least somewhat comfortable. Over 96% agreed that the orthosis their child was using fits well, 90.4% agreed it is easy to put on; 96.6% agreed it is easy to take off; 88.9% agreed it is easy to keep clean; and 89.5% reported that the weight was manageable.

One or more problems with the materials and components of the orthosis were reported by 39.2% of respondents. These included: broken or overstretched straps (13.8%); broken buckles or fasteners (6.9%); broken bar (3.6%); broken connection mechanism (7.5%); too soft (4.2%) or too hard (10.8%) shoe material; and other broken or lost components (6.6%). The child's foot slipping out of the orthosis was reported by 18.9% of respondents.

Over half of respondents (51.6%) stated that their child had experienced skin irritations and/or blisters. Skin problems occurred mostly at the beginning of orthosis use (29.9%). They were also reported when: the child received new shoes (15.4%); the shoes were too small (9.7%); the child began to actively kick (7.4%); and when the child was able to walk in the orthosis (2.8%). The blisters and irritations primarily occurred at the back of the heel (24.2%) and at the front of the ankle (20.8%). However, they were also reported to occur on the side of the foot (11.4%), over the big toe (6.8%), and in other locations (12.3%). To manage skin problems, 27.6% of parents reported adding materials such as Moleskin, Aliplast, or Platizote to their child's shoes.

Physicians, orthotists, and parents can use these findings to be aware of common obstacles to orthosis adherence so that these challenges can be anticipated and managed.

Developed quality register for orthoses in CP

Mr Michael Ceder BSc¹, MR Fredrik Bergljung BSc²

¹Department of Rehabilitation School of Health and Welfare JÖNKÖPING UNIVERSITY, Jönköping, 551 11, Sweden. ²Aktiv Ortopedteknik Lund University Hospital, Lund, 221 85, Sweden

Abstract

Developed quality register for orthoses in CP

CPUP is a Swedish Quality register and national follow-up program covering more than 95% of all persons with Cerebral Palsy in Sweden. The overall objectives of the CPUP are: Through continuous and long-term examination of the musculoskeletal system in combination with, if necessary, early treatment try to prevent the occurrence of hip luxation and other secondary complications, thereby optimizing function and improving quality of life for people with CP. Another goal is to increase knowledge about CP and the effects of different treatment interventions. Also, we aim to improve cooperation between different professional categories around people with CP. Several results have been published in scientific journals. For example:

• The proportion of children with hip dislocation (hip displacement

LED) has decreased from 9% to 0.6%.

• The proportion of children with severe contractures

(joint stiffness) has decreased.

- The proportion of children with scoliosis has decreased.
- The percentage of children with CP who report pain

is lower than in most international reports.

The database continues to develop. There are multiple professionals who take part of the register treating children with Cerebral Palsy. Interventions and patient status are registered continuously. CPOs have been involved in the organization committee since 1994, and time found the need for more detailed information about the orthotics used for those children. In 2017, a group of Orthotists, physiotherapists, and Occupational therapists started working on a new evaluation formula. In 2020, a web-based evaluation form was introduced for all clinicians in Sweden. The form is based on International Standards (ISO) and Goals of Treatment – ICF. With the new orthoses form we register what type of orthosis, Material properties, and more that is used for children in different GMFCS levels,

and ages. We also specify their function in more detail according to ISO standards. As the database is national, we can see differences in delivered orthotics in different regions of Sweden. The proportion of children born between 2004 and 2019 in GMFCS I-V who in 2020 reported using ankle-foot orthosis (AFO) in each region. Total number of children reported in 2020 in each region in brackets.

With the help of the register, future studies and statistics can hopefully show the appropriate choice of orthosis for specific goals. Also, we will be able to differentiate between reached goals, function, Features of the orthosis and more. In 1994 the ISPO consensus report stated the need for more information in scientific papers. Not much has happened since then. Maybe the CPUP register is a method to finally do something about this?

Fredrik Bergljung

CPO, BSc

Adjunct Lecturer

Senior Orthotist

CPO, BSc

Cognitive and developmental barriers with pediatric prosthetic training: Physical Therapy Perspective

Brittany Guidry DPT, Sharon Malek DPT, Kelly Phelan DPT, Brittni Willis DPT

Texas Children's Hospital, Houston, TX, USA

Brittni Willis

Short Bio of all Presenting Authors

Brittany, Sharon, Kelly and Brittni are Physical Therapist's apart of Texas Children's PM&R's Limb Difference Clinic. They also treat patients with limb difference and limb loss in the Outpatient Therapy clinic.

Abstract

This presentation will include a review of the current literature regarding the relationship between cognition, physical therapy and prosthetic training in pediatrics. It will also discuss factors that impact progress with prosthetic training regarding cognition and development and provide case examples as well.

Femoral Duplication: An Underappreciated Variant of Tibial Hemimelia

Carol Wise PhD¹, Kristhen Atala BS¹, Nathan Heineman MD¹, Corey Gill MA/MD^{1,2}

¹Scottish Rite for Children, Dallas, TX, USA. ²UT Southwestern Department of Orthopaedic Surgery, Dallas, TX, USA



Corey Gill

Short Bio of all Presenting Authors

Corey S. Gill, MD/MA, is a Pediatric Orthopaedic Surgeon at the Scottish Rite Hospital for Children and an Assistant Professor in the Department of Pediatric Orthopaedic Surgery at UT Southwestern Medical Center in Dallas, Texas. He completed undergraduate education at the University of Georgia, followed by medical school and orthopaedic residency at Washington University in St. Louis. He completed a Fellowship in Pediatric Orthopaedic Surgery at the Scottish Rite Hospital for Children, and worked as the Medical Director of Pediatric Orthopedics at Medical City Children's Hospital Dallas prior to his current position at Scottish Rite Hospital. Dr. Gill is a Fellow of the American Academy of Orthopaedic Surgeons (AAOS) and is an Active Member of the Pediatric Orthopaedic Society of North America (POSNA) and the Association of Children's Prosthetic-Orthotic Clinics (ACPOC). He serves on the ACPOC Board of Directors and the POSNA Pediatric Orthopaedic Global Outreach (POGO) Committee. Clinically, Dr. Gill treats patients with a variety of congenital and acquired pediatric orthopaedic conditions such as musculoskeletal trauma, hip dysplasia, and clubfoot. He has a particular interest in treatment of children with lower limb differences who have undergone limb ablation surgery and/or utilize prosthetic devices.

Abstract

Introduction: Femoral duplication or bifurcation is a rare condition previously reported in isolated case reports of various complex congenital anomalies such as Gollop-Wolfgang complex. The purpose of this study was to better define clinical and genetic presentation of a cohort of femoral duplication patients treated at a single institution.

Methods: Retrospective chart review was performed on pediatric patients with femoral duplication or bifurcation treated at a single institution from 1970-2022. Demographic, clinical, surgical, and genetic data were collected and analyzed.

Results: 11 patients were identified with femoral duplication. All of these patients had a concurrent diagnosis of Jones type I tibial hemimelia and comprised 11/46 (24%) of the overall institutional Jones type I tibial hemimelia population. Patients were most commonly female (64%) and Black (55%). 4/11 (36%) of femoral duplication patients also had congenital upper extremity anomalies. All patients underwent knee disarticulation amputation and 7/13 (54%) of limbs underwent excision of the duplicated femur. 5/11 femoral duplication patients underwent genetic testing, and increased copies of the BHLHA9 gene was noted in three.

Conclusions: Femoral duplication is a relatively common but underappreciated variant of Jones type I tibial hemimelia. Patients with femoral duplication often benefit from excision of the accessory femur. Increased BHLHA9 gene dosage contributes to formation of the duplicated femur in some patients, and clinical genetic testing is warranted in this population.

Significance: A more thorough understanding of the clinical presentation and pathophysiology of femoral duplication in pediatric patients will help to optimize current orthopaedic care and may lead to future treatments designed to address the genetic contribution to this rare condition.

Unique prosthetic suspension designs: Meeting patient goals

Beth Petrovic CPO

Hanger Clinic, Oak Park, IL, USA

Abstract

Prosthetic design for pediatric patients can be complex, especially when considering comfort, function, and patient specific goals. As patients age, their personal goals weigh in heavily when choosing a prosthetic design. Working with the patient and their family to better their concerns with the current prosthesis and what they would like to change gives the prosthetist the opportunity to be creative in the suspension design.

The purpose of this presentation is to show three unique prosthetic suspension mechanisms used in clinic for patients with varying physical presentations. Each of the three cases with start with background on diagnosis, patient specific goals, and previous suspension mechanisms of their prosthesis. The first patient (patient 1) to be discussed with be a 13-year-old boy with proximal focal femoral deficiency (PFFD) who has history of using an ischial containment (IC) style prosthesis with a TES belt. The patient's goals include moving away from using the TES belt for suspension. The second to be discussed (patient 2) is a 16-year-old boy with a with rotationplasty procedure who previously used multiple straps for provide anatomical suspension. The third case will be a 15-year-old boy (patient 3) with bilateral Symes amputations who had previously worn bilateral patellar tendon bearing sockets with a pelite insert and stovepipe for anatomical suspension. The primary concern for this patient and his family was hygiene and the odor that comes from his pelite inserts.

Each case came with its own unique challenges that were addressed in clinic during fitting appointments. In some cases, multiple iterations were required to meet appropriate outcome when it came to patient comfort and proper function of the prosthesis. Patient 1 was fit with a IC style socket with a pelite insert and stovepipe to provide anatomical suspension over his malleoli. Patient 2 was fit with a proflex boot that suspended over his calcaneus. Patient 3 was fit with a suction sockets with seal in liner and stovepiped proflex flexible inner. Ultimately, all three patients were fit with prostheses that better aligned with their personal goals while allowing them to maintain their high activity level.

Retrospective Evaluation of Targeted Reinnervation at the Time of Major Limb Amputation as a Means to Avoid Neuroma Pain and Phantom Limb Discomfort

Dr. TJ Utset-Ward M.D., Daryn Strub BA, CRC, Dr. Thomas Scharschmidt M.D., Dr. Kirtsen Tulchin-Francis PhD

Nationwide Children's Hospital, Columbus, Ohio, USA



Dr. TJ Utset-Ward

Short Bio of all Presenting Authors

TJ Utset-Ward is an orthopedic oncologist with a particular interest in pediatric sarcoma. He completed a Musculoskeletal Oncology surgical fellowship at The Ohio State University and continued additional pediatric-specific training at Nationwide Children's Hospital as a Pediatric Orthopedic Oncology Fellow. He previously completed residency at the University of Chicago, medical school at Vanderbilt University, research fellowship at Moffitt Cancer center and Master of Business Administration at Vanderbilt University. His interests include osteosarcoma and osteosarcomagenesis, exosomes, clinical outcomes studies, and translational innovations such as 3D printing for oncologic applications. He is interested in maximizing the lives and function of children undergoing limb salvage and amputations for trauma and cancer.



Daryn Strub

Short Bio of all Presenting Authors

Daryn is a Clinical Research Coordinator at Nationwide Children's Hospital. He specializes in pediatric orthopedic surgery research and pediatric orthopedic oncology research. He completed his bachelor's degree in Biological Sciences at Miami University. His medical interests include osteosarcoma, total hip arthroplasty, degenerative hip diseases, lower extremity amputation, and sports medicine.



Dr. Thomas Scharschmidt

Short Bio of all Presenting Authors

Thomas Scharschmidt is the director of the Pediatric Orthopedic Oncology Program at Nationwide Children's Hospital and a Professor in Orthopaedics at The Ohio State University Medical Center and James Cancer Hospital. His clinical interests include bone and soft tissue sarcomas in adults and children, benign bone and soft tissue tumors in adults and children, complex limb reconstruction, advanced reconstruction options in the growing child, care of the oncologic amputee patient and spine tumors.



Dr. Kirtsen Tulchin-Francis

Short Bio of all Presenting Authors

With nearly 25 years of experience in biomechanics, Kirsten Tulchin-Francis, PhD, has been studying the science behind how children and young adults with orthopedic and neurological conditions walk, jump and play through motion capture. MoCap, as it is frequently referred in the movie and video game industry, uses high-speed cameras, special force sensing plates in the floor and computers to track the 3D movement of the head, arms, legs, and feet as kids walk, squat, bend and run. Along with doctors, physical therapists, engineers, and other researchers, Dr. Tulchin-Francis studies how surgery and other treatment options improves the function and lives of young patients. She holds Bachelor and Master of Science degrees in biomedical engineering and a PhD in Kinesiology- Biomechanics.

Abstract

Purpose: Amputees frequently suffer from chronic post-amputation pain in the form of neuroma-related residual limb and phantom limb pain (PLP). Targeted muscle reinnervation (TMR) is a technique whereby transected nerves are transferred to nearby motor nerves in order to promote healing, prevent neuroma formation and PLP. The purpose of this study was to report the outcomes of TMR in measures of PLP and residual limb pain in a series of pediatric patients.

Methods: A series of pediatric patients undergoing major limb amputation for various diagnoses who received concurrent TMR were screened for eligibility. Patients were included if they had a minimum of one year of post- operative follow-up and completed appropriate follow-up questionnaires. Primary clinical outcomes included the incidence of symptomatic neuromas, PLP, residual limb pain, narcotic use and neuromodulator use. A follow-up phone survey was conducted assessing five Pediatric PROMIS metrics adapted to assess residual limb and phantom limb pain.

Results: Nine patients (7 male, avg. age = 16.83 ± 7.16 years) were eligible and met inclusion criteria. Average time between surgery and phone follow-up was 21.3 ± 9.8 months. Average PROMIS Pediatric t-scores for measures of Pain behavior, interference, quality – affective, and quality – sensory for both PLP and residual limb pain were nearly 1 standard deviation lower than the United States general pediatric population. One patient developed a symptomatic neuroma 1 year after amputation with concurrent TMR.

Conclusion: Compared to the adult sample of 51 patients reported by Valerio et al, the patients treated with TMR at NCH showed similar phantom limb pain PROMIS t- scores in pain behavior (50.1 vs 43.9) and pain interference (40.7 vs 45.6). Scores correlated with residual limb pain as well: pain behavior= 36.7 vs 38.6, pain interference= 40.7 vs 42.7. These were all more than one standard deviation lower than the general adult amputee sample. Additionally, residual limb and PLP t-scores for pain quality (sensory and affective) were less than 50.

Significance: Concurrent TMR at the time of amputation is feasible, safe, and should be considered in the pediatric population. These results suggest that among the pediatric population TMR provides similar benefits in reducing residual limb and phantom limb pain as has been observed in adults.

And Then There Were None - Elective Amputation & amp; Prosthetic Decision Making

Aaron Fitzsimmons CP/OT

Amputee Blade Runners, Nashville, TN, USA

Aaron Fitzsimmons

Short Bio of all Presenting Authors

I have a BS from MTSU, a BS in Occupational Therapy from UT medical School, and a degree in Prosthetics from the University of CT. I worked for 2 years as an OT and 20 years as a CP. I completed my residency under Ronney Snell CPO and ran the St Jude amputee clinic with him for 3 years. I founded Amputee Blade Runners 501c3 in 2009 charity organization after 6 years of mission work in Haiti, Guatemala, and Panama. I lecture as adjunct faculty at Belmont DPT program, TSU DPT, and Vanderbilt Engineering. I practiced in private practice for 6 years and then started Amputee Associates to establish and operate physician based prosthetic clinics. I run 9 prosthetic clinics in 6 different states. My goal is to establish prosthetics as a recognized "allied healthcare provider" and not the "vendor status" we currently occupy in the healthcare system.

Abstract

The Problem:

At approximately age two, this young boy's gait became concerning. He fell frequently, had a poor stance, and off-loaded to the right side. Physicians discovered lower extremity bowing and atrophy on the right side. Contractures began on the right side first, and eventually the left. Despite consultations with countless specialities and facilities throughout the US, no diagnosis was provided. He began using a variety of assistive devices during this time, including AFO, canes, scooters, segways, & wheelchairs. During this time the family privately began to consider amputation. At age thirteen, this young man and his family asked his orthopedic surgeon for his thoughts on amputation. He referred the family to ABR to explore the possibilities of life in prosthetics.

During the initial consultation with the family, I recommended they talk to other families in the prosthetic community, particularly those with children who had bilateral amputations performed electively. The family was cautious since amputation is irreversible, and with no diagnosis there is no guarantee that the contractures would not progress. I also recommended consultation with other surgeons, including fellow ACPOC members, Drs Westberry & Gill.

The Solution

In August, 2022, Dr Westberry performed a knee disarticulation on the right side and a Boyd on the left. This was done after presenting his thoughts and soliciting feedback at the 2022 ACPOC conference. Three months later our patient had lost 20 pounds but was ready to be casted for his first prosthetic legs. The weight of his prostheses was a concern, and I was grateful that the full femur and cancellous were fully intact, permitting the possibility of skin fit, anatomic suspension on both legs. His left knee had a 30° degree contracture at the time of his November casting. Ten months later he has been able to reduce that contracture to 6°. On his knee disarticulation side, he has a sub-ischial containment skin-fit socket. While I frequently advocate against microprocessor knees, especially for children, I tried one for this young man after a short period of time on a mechanical knee. Due to many years of immobility, it was difficult for him to maintain balance. He struggled to control the mechanical knee at times, causing the leg to buckle. My goal is to be able to transition him back into a mechanical knee as his strength and proprioception improve. On his left side, he has a custom foam liner and anatomic suspension. Prior imaging showed ligaments around his knee and I made the conscious decision to provide lower trim lines to encourage greater strength and range of motion in the knee. Within two weeks of wearing prostheses he was walking unassisted. He is now back to pre-surgery weight. Despite the increase in weight I have not had to recast him, though have had to remake sockets due the improvement in his contracture. Though his journey has been long and is not over, this young man is confident the decision to amputate was the best decision he ever made.

Keynote Presentation: Physical Activity, Sports, and Recreation Participation in Children and Adolescents with Physical Disabilities: What Progress Have We Made and Where Do We Go from Here?

Dr. Stephanie Tow MD

University of Colorado, Aurora, CO, USA. Children's Hospital Colorado, Aurora, CO, USA



Dr. Stephanie Tow

Short Bio of all Presenting Authors

Stephanie Tow, MD, FAAPMR, CAQSM is an Assistant Professor in the Department of Physical Medicine & Rehabilitation (PM&R) at the University of Colorado and Departments of Pediatric Rehabilitation Medicine, Orthopedics Institute - Sports Medicine Center, and Pain Medicine at Children's Hospital Colorado. Dr. Tow completed her undergraduate degree in neuroscience at Johns Hopkins University, after which she was awarded a Fulbright Scholarship focused in the field of education and teaching in Hong Kong. She earned her medical degree at the University of Medicine and Dentistry of New Jersey - New Jersey Medical School and completed her residency and chief residency in physical medicine and rehabilitation at UT Southwestern. She subsequently performed her pediatric rehabilitation medicine fellowship at the University of Colorado and Children's Hospital Colorado and then her sports medicine fellowship at Children's Mercy Hospital in Kansas City. Dr. Tow is board-certified by the American Board of Physical Medicine & Rehabilitation in PM&R, Sports Medicine, and Brain Injury Medicine. She is currently the Head Team Physician for Team USA Paralympics Swimming's National Team, as well as a National Medical Classifier for US Paralympics Swimming. She also volunteers as a sit ski instructor with the National Sports Center for the Disabled. She has been involved with various adaptive sports organizations as a physician, medical director, and/or volunteer, and also was previously the Director of the Dallas-Fort Worth Adaptive Sports Coalition from 2020 - 2022. She has a passion for

working with athletes of all abilities, including adaptive and Para sports athletes, and is an advocate for equitable access to sports and sports medicine resources for all athletes.

Abstract

There are many benefits of physical activity, sports, and recreation participation for children and adolescents across the entire range of functional abilities. Yet only about 25% of children in the United States participate in appropriate amounts of physical activity, and this percentage is even lower for children with physical disabilities. Youth with disabilities have some unique considerations when it comes to physical activity, exercise, and sports participation, but these considerations should not be barriers for participation. It is critical for all healthcare providers caring for youth with disabilities to promote physical activity, sports, and/or recreation participation to encourage healthy lifestyles and benefits of participation at a young age. Clinicians should be familiar with physical activity guidelines for all age groups and have expertise of a breadth of medical conditions to provide customized recommendations to promote physical activity, exercise, and advocate for resources to facilitate equitable access and participation in physical activity and sports opportunities. Opportunities and resources for people with disabilities to participate in physical activity, sports, and recreation are continuing to increase in the United States, but there are still any areas needing further advocacy.

This 45-minute keynote presentation will take the audience on a journey reviewing the past, current, and future directions of physical activity, sports, and recreation participation in children and adolescents with physical disabilities in the United States. We will discuss the benefits of physical activity, sports, and recreation participation, the current physical activity guidelines for different age groups, a broad overview of important medical considerations for different medical conditions, and potential methods clinicians can use when meeting with patients and their families in clinical settings to assess the status of and promote physical activity, sports, and recreation participation. Areas of need for advocacy will also be discussed, as well as additional resources for clinicians to learn more to support the needs of their patients.

Ambulatory Considerations and Lower Extremity Orthotic Interventions for Children with Autism

Ms. Heather Willets Masters of Prosthetics-Orthotics

Hanger Clinic, Lafayette, Colorado, USA



Ms. Heather Willets

Abstract

Gait deviations, including toe walking and excessive medial ankle collapse secondary to sensory seeking behaviors, are not uncommon in the pediatric population with a diagnosis of Autism Spectrum Disorder (ASD). This presentation (or poster) serves to review the current literature on this topic, including areas where continued research is indicated, and proactive and preventative measures for the treatment team to consider.