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# Advances in Spinal Muscular Atrophy (SMA) Management

Brian Snyder, MD, PhD, Brandon Ramo, MD, Leslie Nelson, PT, PhD, Ronni Rowe, OT, APT, and James Wynne, CPO

#### Short Bio of all Presenting Authors

Brian D. Snyder, M.D., Ph.D. is a Board Certified Pediatric Orthopedic surgeon at Boston Children's Hospital, where his clinical practice focuses on spinal deformity related to congenital and neuromuscular etiologies, hip dysplasia and acquired deformities about the hip, cerebral palsy and pediatric trauma. Dr. Snyder is also a Professor of Orthopedic Surgery, Harvard Medical School and Director of the Orthopedic Biomechanics Laboratory at the Beth Israel Deaconess Medical Center.

Brandon Ramo, MD is the Chief Quality Officer and a pediatric orthopedic surgeon at Scottish Rite for Children. He specializes in Early Onset Scoliosis and other Spine Disorders, Pediatric Operative Fracture Management, and Osteogenesis Imperfecta.

Dr. Leslie Nelson, PT, PhD, is a physical therapist at the University of Texas Southwestern Medical Center in Dallas, Texas where she serves as Assistant Faculty in the Department of Physical Therapy. She has specialized in neuromuscular disorders since 2004, with special interest in clinical outcomes for neuromuscular populations, specifically DMD and SMA.

Ronni Rowe, OT, APT is an occupational therapist at Texas Scottish Rite Hospital specializing in the pre-surgical planning clinic and serves as an Assistive Technology Professional providing support with mobility needs.

Jim is the Director of Education and Resident Director for OrthoPediatrics Special Bracing. He specializes in the nonoperative management of idiopathic, neuromuscular and congenital scoliosis.

## Abstract

Goals and Learning objectives:

- 1. **Understanding SMA:** Attendees will be able to explain the genetic basis, including the role of the SMN protein and how its deficiency leads to motor neuron degeneration.
- 2. Understanding current Pharmacological Treatments: Participants will gain insight into available and emerging therapies for SMA, focusing on their mechanisms of action, and clinical outcomes.
- 3. **Implementing Multidisciplinary Care Strategies:** Attendees will learn how to create effective, individualized care plans that address both mobility and supportive needs.
- 4. 4. **Supportive Care Needs**: Attendees will be able to identify key components of supportive care to enhance the quality of life for SMA patients and their families.

The goal of this 90 min interactive session is to facilitate a comprehensive understanding of current SMA management practices among healthcare professionals.

Spinal Muscular Atrophy (SMA) is a genetic neuromuscular disorder characterized by progressive muscle weakness and atrophy due to the loss of motor neurons in the spinal cord. Recent advances in gene therapies such as Nusinersen (Spinraza), have led to improved motor function and survival rates in infants diagnosed with SMA.

Comprehensive treatment protocols that reflect the unique needs of this patient population need to be developed for the patients, their families and all members of the multidisciplinary team to ensures that patients receive evidence based, patient specific, interventions that address their unique needs.

This proposed multidisciplinary SMA management symposium is an initial step in bringing clinical experts together representing key members of the clinical team: Orthopedic Surgeon, Physical and Occupational Therapists, Orthotist, and patient advocacy to present their experience and findings.

Orthopedic surgeons will discuss their role in leading the team, and managing skeletal complications, including scoliosis and hip dislocation. They will share their guidelines for surgical interventions, preoperative assessments and management such as halo traction, and postoperative rehabilitation.

Physical and Occupational Therapists will discuss their role in enhancing mobility and functional independence both preand post-operatively. They will share their protocols focus on maintaining range-of-motion and strength and the need for regularly scheduled follow up assessments to adapt interventions in response to the patient's evolving presentation.

The Orthotists will discuss bracing goals and design to optimize functional mobility while not restricting movement or respiration in the case of a spinal orthosis to improve sitting balance and control the rate of progression of the scoliotic curve. Current fabrication techniques involving scanning and CADCAM design to be discussed along with ensuring that orthotic interventions are appropriately aligned with the patient's developmental stages and functional goals.

# Pain Management in Pediatric Cerebral Palsy Patients Undergoing Single-Event Multilevel Surgeries Involving the Hip: Efficacy of Post-operative Epidural Analgesia

Daniel Whittingslow, MD, PhD, Camara Wooten, Aaron Williams and Anna Vergun, MD

#### Short Bio of all Presenting Authors

Dr Daniel Whittingslow completed his MD/PhD training at Emory University and the Georgia Institute of Technology in 2021. There he specialized in fabricating novel wearable devices for longitudinal monitoring of musculoskeletal health. He matched into orthopaedic residency at the University of North Carolina Chapel Hill in 2021, and was selected as the research resident for his class with an additional year dedicated to entirely to orthopaedic research. At this time, he plans to pursue a fellowship in spine surgery and is hoping to continue to serve underserved populations by both performing surgery and designing wearable devices to aid in rehabilitation and recovery of his patients.

#### Abstract

#### Introduction:

Surgical intervention for progressive neuromuscular hip dysplasia is common in children with cerebral palsy (CP) to improve their quality of life [1]. However, postoperative pain control remains challenging and is not well-studied in this population [2,3]. This study aims to compare pain management outcomes in CP patients undergoing single-event multilevel surgery (SEMLS) involving the hip, focusing on the impact of epidural analgesia on postoperative pain, narcotic, and Tylenol consumption, as well as length of stay (LOS).

#### Methods:

This retrospective analysis included pediatric CP patients (<18 years) who underwent SEMLS involving the hip at our institution between January 2014 and August 2024. Patients were divided into two groups: those who received epidural analgesia with multimodal pain control (MMPC) and those who received only MMPC (control group). Data on post-operative Tylenol (mg/kg/day), narcotic use (morphine milligram equivalent, MME/kg/day), pain scores, and LOS were extracted from medical records. Repeated measures ANOVA and post-hoc Tukey-Kramer tests were used for multiple comparisons, with adjustments for non-normality and missing data. Chi-square analysis was performed for LOS comparisons.

#### **Results:**

A total of 181 patients met the inclusion criteria, with 128 receiving both MMPC and epidural analgesia post-operatively, and 53 receiving only MMPC. **Overall pain scores were low**, ranging between 0-2 on a 10-point scale. Pain scores were significantly higher on postoperative day (POD) 3 in the epidural group compared to the control group (1.23 $\pm$ 2.20 vs. 0.34 $\pm$ 1.30, p<0.05). **Patients in the epidural group exhibited significantly greater narcotic use post-operatively**, with the largest divergence beginning on POD3 (0.49 $\pm$ 0.42 vs. 0.08 $\pm$ 0.48 MME/kg/day, p<0.001), and a diminishing difference by POD7 (0.09 $\pm$ 0.24 vs. 0.01 $\pm$ 0.03 MME/kg/day, p<0.01). Tylenol consumption was also higher in the epidural group on POD3 (51.79 $\pm$ 1.18 vs. 38.99 $\pm$ 2.84 mg/kg/day, p<0.0001), but beyond POD7, the non-epidural group used more Tylenol (40.54 $\pm$ 1.57 vs. 61.10 $\pm$ 1.59 mg/kg/day, p<0.05). On average, **the epidural group had a longer hospitalization** (7.4  $\pm$  13.8 days vs. 4.2  $\pm$  3.9 days, p<0.01), though the proportion of patients staying beyond POD4 was not significantly different between the groups.

#### Discussion:

This study shows that CP patients undergoing SEMLS who received epidural analgesia had greater postoperative narcotic needs and longer hospitalizations compared to those without an epidural. The comparable pain scores between the two groups raise questions about the overall efficacy of epidurals in this population. The increase in pain scores and analgesia requirements on POD3 aligns with the departmental policy of removing epidurals on POD2. However, the criteria for administering epidural analgesia are not standardized and often depend on patient and family preference due to limited research in this area. This study unexpectedly found that the anticipated benefits of epidural analgesia for pain control and earlier discharge were not realized.

#### Conclusion:

Pediatric CP patients undergoing hip osteotomies as part of SEMLS who received epidural analgesia reported similar pain scores to those without an epidural, but required more narcotics and had a longer LOS. These preliminary findings highlight the need for further research to optimize postoperative pain management strategies in this vulnerable population to improve outcomes.

# A Different Approach: Use of a Custom-Molded TLSO as Compared to Traditional Bracing for Pediatric Neuromuscular Scoliosis

Abbey Meyer, LCPO, David Farbo, PhD, Kristy Reyes, BS, Lauren Lamont, MD and Ybarra Cristian, MD

#### Short Bio of all Presenting Authors

Abbey Meyer is a certified orthotist-prosthetist from Fort Worth, TX with a passion for treating scoliosis and spine deformities. Diagnosed with scoliosis at age 10, Abbey wore a Boston back brace for 4 years inspiring her to pursue a career in orthotics. After receiving her Bachelor's degree from UT Southwestern in Orthotics and Prosthetics in 2010, she completed her orthotics and prosthetics residencies and started her career at Texas Scottish Rite Hospital for Children in Dallas, TX focusing on bracing and treatment of adolescent idiopathic scoliosis and other musculoskeletal conditions. Her own scoliosis curves progressed into adulthood ultimately needed a posterior spinal fusion from T9 to L4 in 2023. Abbey currently practices as the lead orthotics and prosthetics clinician at Cook Children's Hospital in Fort Worth, TX and enjoys spending time outdoors with her husband, and three kids.

## Abstract

Neuromuscular scoliosis (NMS) is a form of scoliosis that results from a lack of muscular control or spasticity of the muscles caused by a neurological or degenerative muscular condition. Neuromuscular disorders can affect a child's body in many ways such as muscle tightness and spasticity, which can interfere with the ability to walk and perform everyday tasks. Management of NMS curves is often difficult due to large curve magnitudes, patient tone, and other complications from the patient's underlying disease.12 The goal of bracing this population includes improved positioning, improving quality of life, and delaying surgical intervention as compared to a reduction in curve magnitude in the idiopathic population. Traditional, rigid plastic bracing has shown some success but is frequently abandoned due to patient intolerance and complications.3 There is limited data on the use and compliance of back bracing in the pediatric NMS population, and the data that is available shows mixed results.456

The purpose of our review is to assess if the treatment option of utilizing a custom-molded Thoracic-Lumbar-Sacral Orthosis (TLSO) brace within a pediatric NMS population can improve outcomes. This particular brace is created from molded plastic and custom made to fit each patient. The brace is designed with a posterior thermoplastic shell and anterior flexible apron traditionally used for management of proprioception, tone, and stability of the spine. Our study review includes a sample size of 98 pediatric patients diagnosed with NMS at Cook Children's Medical Center of Fort Worth, TX, from June 2023 to September 2024. Of the 98 patients reviewed, 19 are identified as being prescribed with a custom-molded TLSO brace and 79 are prescribed with another traditional type of back brace for their NMS. Demographic and radiographic data were compared between the two groups. Treatment outcomes, risk factors, and curve progression were also assessed.

We hypothesize that the custom-molded TLSO will have an increase in patient tolerance, decrease in rate of bracing complications, and delay the time to surgical intervention of their scoliotic curve as compared to patients who are treated with traditional bracing.

# Early Brace Treatment: The New Standard for Adolescent Idiopathic Scoliosis?

Karina A. Zapata, PT, DPT, PhD; Megan Johnson, MD; JP Rathbun, BSA; Donald Virostek BS, CPO; Chan-Hee Jo, PhD; Daniel J. Sucato, MD, MS

#### Short Bio of all Presenting Authors

Dr. Karina Zapata earned her Doctorate of Physical Therapy at University of Southern California in 2007. She completed her Ph.D. at Texas Woman's University in 2013. She has been employed by Scottish Rite for Children since 2007, where she is currently a Senior Clinical Scientist. Her research is focused on pediatric orthopedics, primarily the spine. She is also Assistant Professor at the University of Texas Southwestern.

John-Patrick "JP" Rathbun earned his Bachelor of Science and Arts in Biology, with a minor in Business, from the University of Texas at Austin. Since 2024, he has been a Clinical Orthopedic Research Assistant with the Spine Research Team at Scottish Rite for Children.

## Abstract

Introduction: Brace treatment in skeletally immature patients for curves <25° is increasing. However, no direct comparisons exist between bracing adolescent idiopathic scoliosis (AIS) curves <25° (early) versus observation until bracing at  $\geq$ 25° (standard). The purpose of this study was to compare 1) curve improvement  $\geq$ 6° and 2) progression to a surgical magnitude of 45°, between early versus standard brace treatment.

Methods: A retrospective review was performed among patients Risser 0-1 with AIS curves 15-24° at initial visit who were followed until skeletal maturity or surgery. Patients who were prescribed rigid thoracolumbar sacral orthoses (TLSO) for curves 15-24° from 2015-2019 (early brace group) were compared to a historical control observed until TLSO prescription at ≥25° from 1990-2005 (standard brace group). A sub-analysis of open triradiate cartilage status was performed.

Results: 528 patients (436 F [82%], 92 M) were included. At initial visit, the early brace group had larger curves and a greater percentage with open triradiates than the standard brace group (22° vs. 19°, p < 0.001). 32% of patients in the standard brace group eventually required brace treatment at a higher curve magnitude (30° vs. 22°, p < 0.001) and a more advanced maturity (36% vs. 63% open triradiates, p < 0.001) than the early brace group. The early brace group had greater curve improvement  $\geq$ 6° (19% vs. 1%, p < 0.001) with an odds ratio (OR) of 25.39 (95% CI 9.05-106.04) and less curve progression  $\geq$ 6° (OR 0.29, 95% CI 0.20-0.41) but not to a surgical threshold (6% vs. 10%, p = 0.138) than the standard brace group (Table).

Patients with open triradiates in the early brace group progressed to a surgical threshold significantly less than those in the standard brace group (9% [12/120] vs. 20% [25/128], p = 0.018) with an OR of 0.42 (95% CI 0.19-0.86), especially among those with thoracic curves 20-24° at initial visit (13% [7/54] vs. 43% [15/35], p = 0.001) with an OR of 0.20 (95% CI 0.07-0.54).

Conclusions: Early brace treatment of AIS curves 15-24° is superior to observation until 25° in skeletally immature children with a 25-fold increased likelihood of improving curves and reducing curve progression to a surgical magnitude by >50%.

Significance: Early brace treatment is recommended for families' whose brace treatment goals include possible curve improvement and as standard-of-care to prevent progression to surgery in patients with open triradiates.

-	Early brace (n=207)	Standard brace (n=321)	p-value
Biologic Sex			
Female	80% (n=167)	83% (n=269)	0.355
Male	19% (n=40)	16% (n=52)	
Initial age (yrs)	12.4±1.2 (n=207)	12.6±1.2 (n=321)	0.047
Initial primary curve			
Thoracic	43% (n=89)	51% (n=164)	.069
Lumbar/Thoracolumbar	57% (n=118)	48% (n=157)	
Initial Risser stage			
0	85% (n=176)	81% (n=261)	0.249
1	14% (n=31)	18% (n=60)	
Initial triradiate cartilage			
Open	62% (n=130)	46% (n=128)	<0.001
Closed	37% (n=77)	53% (n=150)	
Initial menarchal status			
Pre	76% (n=128)	72% (n=190)	0.510
Post	23% (n=39)	27% (n=73)	
Initial BMI (kg/m2)	18.2±2.5 (n=199)	18.9±3.8 (n=302)	0.008
Initial curve magnitude (°)	21.8±2.1 (n=207)	19.3±2.9 (n=321)	< 0.001
C-DAR	3.7±0.9 (n=207)	3.3±0.8 (n=321)	< 0.001
Growth (cm)	10.2±5.9 (n=199)	12.3±20.4 (n=296)	0.082
Final curve magnitude (°)	24.9±11.4 (n=207)	28.9±10.7 (n=321)	<0.001
Total curve progression (°)	3.1±11.2 (n=207)	9.6±10.0 (n=321)	< 0.001
Curve improved ≥6°	19% (n=40)	1% (n=3)	< 0.001

Curve stable	49% (n=103)	38% (n=122)	0.008
Curve progressed ≥6°	30% (n=64)	61% (n=196)	< 0.001
Final curve ≥30°	26% (n=54)	41% (n=132)	<0.001
Final curve ≥45°	6% (n=13)	9% (n=32)	0.138
Sub-analysis: Open Triradiates Final curve ≥45°	(n=120) 9% (n=12)	(n=128) 20% (n=25)	0.002
Sub-analysis: Open Triradiates: Thoracic curves 20-24° Final curve ≥45°	(n=54) 13% (n=7)	(n=35) 43% (n=15)	0.001

Initial=time of brace prescription; Final=brace discontinuation, skeletal maturity, or progression to surgery. BMI=Body Mass Index. C-DAR=coronal deformity angular ratio.

# Halo Gravity Traction: Application of Best Practice Guidelines in 3 Spine Centers of Excellence

Lauren Levey, MSPO, CPO, Kaila Devine, MSN, CRNP, Alison Troilo, PT, DPT, Don Virostek, CPO, LPO and Richard Welling, MSPO, CPO

#### Short Bio of all Presenting Authors

Lauren has been with Boston Orthotics & Prosthetics (Now OrthoPediatrics Specialty Bracing) for over 8 years, based at the Children's Hospital of Philadelphia. Lauren's passions and specializations include orthotic treatment of complex limb deformities, Spina Bifida, and pediatric prosthetics. Being at CHOP, Lauren has a special affinity for challenging presentations and complex cases that require inventive problem solving, multidisciplinary teamwork, and creative innovations.

Kaila works as an inpatient Nurse Practitioner, aiding in coordinated care for patients undergoing spine deformity correction at the Children's Hospital of Philadelphia.

Alison works as a Physical Therapist at the Children's Hospital of Philadelphia, specializing in the inpatient and acute care settings.

Don Virostek, C.P.O., L.P.O., is certified in both orthotics and prosthetics. He has been with Scottish Rite for 20 years and has a passion for working with children. He received his Bachelor of Science in Orthotics and Prosthetics in 1988 from UT Southwestern Medical Center. Don has been actively involved in the exam process for the profession for over 20 years and was the President of the American Board for Certification for Orthotics, Prosthetics and Pedorthics in 2012. He enjoys staying active in all aspects of both the orthotics and prosthetics departments with a strong interest in scoliosis treatment and lower extremity bracing. When away from work, he enjoys spending time outdoors with his wife, three boys and their growing families.

#### Abstract

Halo Gravity Traction (HGT) has been used to treat children with severe spinal deformity for decades (BD Roye, 2020). Roye et al. established best practice guidelines for application of HGT via a modified Delphi consensus survey, including indications, goals, pre-operative evaluations, protocols, and complications. Li, et. Al. further described the pathway to implement HGT treatments at a new institution, including equipment modifications, clinical protocol review, and care coordination between a large multidisciplinary team.

In this Symposium, we will discuss applications of these best practice guidelines at 3 major Spine Centers of Excellence: Children's Hospital of Philadelphia, Texas Scottish Rite Children's Hospital, and Children's Healthcare of Atlanta. Representatives from Physical Therapy, Orthopedics, and Orthotics will discuss applications of these best practice guidelines, including:

- Evaluation and patient selection
- Surgical planning
- Halo application and techniques
- Physical Therapy assessment
- Equipment Modifications
- Case Reviews
- "When things go wrong"

This symposium will also examine aspects of comprehensive care that make these cases successful and tolerable to the patients, including child life/psychology involvement, daily activities, medication management, and more.

# Development of a Cloud-Based Remote Monitoring System for Halo Gravity Traction

Lydia Klinkerman, BS, Brad Niese, BS, and Jaysson Brooks, MD

#### Short Bio of all Presenting Authors

Lydia Klinkerman is a Clinical Research Coordinator in the Department of Clinical Research, Spine Division, at Scottish Rite for Children. Lydia's research focuses on Idiopathic Scoliosis (both non-operative and operative) and Neuromuscular/Syndromic Scoliosis, with additional work in applied research with devices. She has collaborated with several institutions on research projects most notably, the National Institute of Health (NIH) and the Setting Scoliosis Straight Foundation (SSSF). She holds a Bachelor of Science from Texas A&M University. Lydia has co-authored four published manuscripts and has been co-authored on several abstracts presented at Orthopedic/Pediatric Conferences including the Scoliosis Research Society (SRS), Pediatric Orthopedic Society of North America (POSNA), American Academy of Orthopaedic Surgeons (AAOS), and American Academy of Pediatrics (AAP).

#### Abstract

**Introduction:** Spring based halo gravity traction (HGT) has been utilized at our institution since the 1980s, however to date, no data exists on the actual dynamic forces transmitted to the spine of these children. Children with large stiff curves may undergo inpatient HGT between 4 to 12 weeks; however, this treatment is costly to the hospital system and can disrupt the lives of the patients and their families. In addition, concerns exist on the safety of sending patients home with HGT, given the inability to monitor traction compliance or applied weight. More widespread adoption of HGT might be possible if it could be reliably monitored in a patient's home. In this pilot study we present the findings of a novel cloud-based remote monitoring system used on 4 children undergoing HGT.

**Methods:** The force applied to the spring based HGT system is measured using a load cell sensor; the load cell is hard wired to a load cell conditioner which both powers the load cell and outputs the load using a milli-amp signal into the transmitting unit which uploads the milli-amp value to cloud storage via mobile or WIFI connectivity. In the cloud, this milli-amp signal is converted into pounds-force using the calibration curve of the load cell (Figure). Signals were transmitted to the cloud every minute.

**Results:** After receiving IRB approval, four patients, all female, requiring HGT were consecutively enrolled between June and July 2024. Patients were aged 6, 10, 12, and 13 years old, and diagnoses were infantile idiopathic, syndromic, juvenile idiopathic, and congenital, respectively. For each patient, a remote monitoring system was added to their halo walker and wheelchair. Traction compliance was measurable in all patients during their inpatient HGT treatment. Example Force data for patient #1 during the entire traction period and each minute during a 24-hour period is displayed in the Figure. All patients achieved their goal traction prior to definitive fusion or growing rod instrumentation. The mean curve magnitude pre-HGT was 104 (range 83-120) degrees and at completion of HGT was 78 (range 63 to 87) degrees.

**Conclusion:** In this pilot study, we have proven that traction compliance can be remotely monitored along with the magnitude of traction weight transmitted to the spine.

**Significance:** This is the first study in the literature to describe the safe, remote monitoring of children under HGT. This pilot data will help to guide future outpatient HGT studies.

# Physical Health and Youth Sports in Congenital and Amputated Lower Limb deficiency (PHYSICALL): Results of a Multi-site, Cross-Sectional Study

# Mary Dubon, MD, Rebecca Siegel, MD, Phoebe Scott-Wyard, DO, and Corey Gill, MD, MA

## Short Bio of all Presenting Authors

Dr. Mary Dubon is a Pediatric Sports Medicine and Pediatric Rehabilitation Medicine Physician at Harvard Medical School/Boston Children's Hospital/Spaulding Rehabilitation Hospital and is the Program Director of the Pediatric Rehabilitation Medicine Fellowship Program at Spaulding Rehabilitation Hospital/Harvard Medical School. She is the Associate Director of the Kelley Institute for Adaptive Sports Research through the Spaulding Rehabilitation Network and is actively involved in adaptive sports research, including funded research projects. She is lead site principal investigator of Physical Health and Youth Sports in Congenital and Amputated Lower Limb deficiency (PHYSICALL).

Dr. Becky Siegel graduated Gaucher College with a Bachelor of Arts in Biology. She earned her Doctor of Medicine degree from the Ohio State University College of Medicine. She then completed internship at MetroHealth Medical Center/Case Western Reserve University and Physical Medicine & Rehabilitation residency at Thomas Jefferson University before she completed Pediatric Rehabilitation Medicine fellowship at Spaulding Rehabilitation Hospital/Harvard Medical School. She is board certified in Physical Medicine & Rehabilitation, Pediatric Rehabilitation Medicine, and Brain Injury Medicine. She has Pediatric Rehabilitation clinical expertise in spinal cord injury, congenital limb deficiency/amputation, brain injury, other traumatic injuries, neuromuscular conditions, cerebral palsy, and clinical/procedural tone management.

Dr. Phoebe Scott-Wyard is a rehabilitation medicine specialist at Rady Children's Hospital-San Diego and an associate clinical 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. 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 invested in treating children with limb differences. Before becoming co-director of 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 the President of the Association of Children's Prosthetic and Orthotic Clinics, the only professional organization for pediatric amputee care. She serves as a trainer for peer mentors through the Amputee Coalition and volunteers with Challenged Athlete's Foundation and Camp No Limits.

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 medical school and orthopaedic residency at Washington University in St. Louis, followed by a Fellowship in Pediatric Orthopaedic Surgery at the Scottish Rite Hospital for Children. 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

Children, adolescents, and young adults (youth) with disabilities are thought to participate in sports less than their peers without disabilities. While low rates of physical activity and sports participation are generally cited in youth with disabilities, the topic of sports participation in youth has not been well-explored in the literature.

Physical Health and Youth Sports in Congenital and Amputated Lower Limb deficiency (PHYSICALL) is a multi-site crosssectional research study of sports/physical activity participation and barriers and facilitators to sports participation in youth ages 8-25 with lower extremity amputations/transverse congenital lower limb deficiencies. Data was collected between November 2021 and August 2023 at Boston Children's Hospital, Children's Healthcare of Atlanta, Nationwide Children's Hospital, Rady Children's Hospital, Scottish Rite for Children, and Seattle Children's Hospital.

Our study population included 155 youth (80 male, 73 female, 2 unknown); 126 with acquired lower extremity amputation and 26 with congenital transverse lower extremity limb deficiency. The most commonly played sports were soccer, basketball, and track and field/running/jogging, and baseball.

Goals and Learning Objectives:

1. To provide background information about sports participation in youth with lower limb amputations/transverse congenital limb deficiency and why this information is important.

a. We will discuss the available literature on the topic, including:

i. Available data on physical activity, sports participation, and barriers and facilitators to sports participation in youth with general disabilities.

ii. Limited data that is available on physical activity, sports participation, and barriers and facilitators to sports participation in youth with lower extremity amputations/transverse congenital lower limb deficiency.

b. We will discuss reasons why this knowledge is important:

i. Impact on patients with new or upcoming amputations curious about ability to participate in sports after amputation.

ii. Impact on parents learning about their child's congenital transverse limb deficiency curious about their child's future ability to participate in sports.

iii. Impact on pediatricians performing physical activity counseling for children with lower limb deficiencies.

iv. Impact on sports professionals and sports medicine professionals when considering sports preparation or injury prevention training/education.

2. To describe the methods of our multi-site, cross-sectional research study and general demographics on our study population, including:

a. Methodology including questionnaire development, inclusion/exclusion criteria, and recruitment methods.

b. General demographics including a breakdown of percentages of individuals with different levels of lower extremity amputation.

3. To provide details regarding self-reported physical activity participation among the youth with lower limb amputations/transverse congenital limb deficiency in our study population, including:

a. Before the COVID-19 pandemic.

b. During the COVID-19 pandemic.

4. To provide details regarding sports participation among the youth with lower limb amputations/transverse congenital limb deficiency in our study population, including:

a. General trends of sports participation.

b. Detailed trends of sports participation based on lower extremity amputation/limb deficiency specifics (i.e. bilateral versus unilateral; etc) and geographic location.

c. Use of adaptive equipment/sports prosthetics during sport.

5. To explain barriers and facilitators of sports participation among youth with lower limb amputation/congenital transverse lower limb deficiency.

- a. Reported barriers to sport.
- b. Reported facilitators to sport.

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# Scottish Rite for Children's Learn to Golf Program: For Children with Disabilities, it is more than just a Game

# Dana Dempsey, CTRS

## Short Bio of all Presenting Authors

Dana is a Certified Therapeutic Recreation Specialist who joined Scottish Rite for Children in 1997 to develop and coordinate therapeutic recreation (TR) programs, activities and services utilizing the James F. Chambers Jr. Youth Fitness Park. A graduate from the University of North Texas (B.S. 1986 & M.S. 1991), she had worked in the recreation and leisure profession developing programs in community and clinical settings for people of all ages and abilities for many years prior to working for Scottish Rite. One of the TR programs she created is named Learn to Golf. Established in 1998, it is designed to help hospital patients develop golf skills and garner the rehabilitative benefits of the game. Besides working to promote golf for Scottish Rite patients, Dana also devotes time and energy to promoting accessible golf for people of all ages. She has spoken around the country on inclusion, program development, and accessible golf. With the National Alliance for Accessible Golf (Alliance), she serves on their Executive Board, co-chairs their Education Committee and is also on their Research Committee. Dana also volunteers her time with the U.S. Adaptive Golf Alliance serving on their Women's Adaptive Golf Committee.

## Abstract

Lack of physical activity (PA) is one of the top five causes of death worldwide with the people living on the North American continent greatly impacted. For youth participating in recommended PA, they not only experience physical and mental health benefits, but research has also shown they are likely to have a more active lifestyle as an adult. Studies also show that youth and adults with disabilities participate less in PA when compared to those without. Research has identified many environmental and perceived barriers that impact physical activity levels of a person with a disability. Some of these include accessibility, attitudes of others, poor coordination between organizations, too few qualified staff, time and financial constraints, and lack of knowledge about opportunities for adaptive recreation activities to name a few.

Golf, which has been classified as providing moderate intensity PA on average, can also achieve high intensity or be paced for low intensity. It is an activity that can be played throughout a person's lifespan and can accommodate a wide range of player abilities. Golf facilities are prevalent across North America making for easier access and the golf industry has embraced including "ability" as part of their diversity, equity, and inclusion (DEI) initiatives. Adaptive golf equipment contributes to the enjoyment and success of golfers with disabilities while opportunities to play and compete continue to grow.

Many health benefits associated with PA have been demonstrated by involvement in golf such as cardiovascular benefits, increased longevity, hand-eye coordination, muscle strengthening, and improved motor skills. Mental health benefits can include increased self-esteem, decreased depression, improved mood, increased levels of perceived competence and self-efficacy. Playing golf can provide more opportunities for social interactions which can lead to greater feelings of acceptance, increased social support and reduced feelings of isolation.

This session will describe how in 1998 a Certified Therapeutic Recreation Specialist (CTRS) created and facilitates Scottish Rite for Children's Learn to Golf (LTG) program to help patients they serve reap the benefits of being involved in golf. Designed to reduce or eliminate barriers to access, develop or improve physical skills, social interaction skills, enhance overall quality of life, and aid in connecting with community jr. golf programs, LTG does this by providing four important components: 1. adaptive golf clinics; 2. golf clubs; 3.scholarship funds; and 4. annual Tee Up for Teaching seminar targeting golf instructors and allied health care professionals. Outcomes and benefits will be shared with the audience who will be encouraged to use golf as a tool with the patients they serve.

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# Prenatal Clubfoot Consultations: Barriers to Accessing Information for Expectant Families and Downstream Effects on Bracing Compliance

Rusty Hartman, MS, Brendan Jackson, BS, and Anthony Riccio, MD

# Short Bio of all Presenting Authors

Rusty Hartman earned his Bachelor of Science degree from the University of North Texas in Biochemistry and his Master of Science degree from the University of North Texas Health Science Center in Biomedical Sciences with an emphasis in Integrative Physiology. After finishing his master's Thesis, "The Impact of Early Life Stressors on the Progression of SLE", he joined Scottish Rite for Children in 2021, to continue his passion for research. He currently works as the lead research coordinator at the Foot and Ankle Center of Excellence on campus. His research has focused on improving treatment outcomes in clinical populations inclusive to clubfoot, CMT, and other complex foot and ankle deformities.

## Abstract

**Background:** While our institution has offered prenatal clubfoot consultations (PCC) following ultrasonographic diagnosis of clubfoot deformity since 2016, it remains unclear as to why some families seek out PCC and others do not. Moreover, the effect of PCC on abduction bracing compliance following the Ponseti method remains unstudied. This study therefore aims to identify differences between families who pursue PCC and those who do not as well as to determine the relationship between PCC and bracing compliance.

**Methods:** An IRB-approved retrospective review of patients presenting to a single pediatric institution with idiopathic clubfoot deformity detected on prenatal ultrasound from 2016-2023 was performed. Patients managed via the Ponseti method who began casting prior to 3-months old, with complete bracing compliance data during their initial three months of bracing were included [1]. Bracing compliance was compared between families who sought PCC and those who did not. State Area Deprivation Index (ADI), race, ethnicity, distance traveled to clinic and insurance type were compared between groups [2, 3].

**Results:** 94 infants with an average age of 2.1 weeks (range 0.4-7.9 weeks) at initiation of treatment met inclusion criteria. Of these, the families of 38 sought out a PCC. Patients in the PCC group had higher initial Dimeglio scores (15.41 vs 14.05, p=0.01) and began casting at an earlier age (1.73 vs 2.41 weeks, p=0.01). The PCC group had significantly lower state ADI scores ( $4.16\pm2.18$  vs  $5.63\pm2.74$ ; p=0.007) and were more likely to have commercial insurance (76.32% vs 30.91%, p<0.001) than the non-PCC cohort. All patient families in the PCC cohort were English speaking, while 19.6% were Spanish speaking in the non-PCC cohort (p=.004). No significant differences were found in race, ethnicity, distance traveled to our clinic, or bracing compliance between groups ( $p \ge 0.05$ ).

**Conclusion:** Only 40% of families with a prenatal clubfoot diagnosis requested a PCC. These families started Ponseti casting at an earlier age, had better socioeconomic well-being, were English speaking, and were more likely to have commercial insurance than families not requesting a PCC, though bracing compliance was similar between groups.

**Significance:** Though families seeking PCC did not demonstrate superior bracing compliance, concerning differences in socioeconomic status, primary language, and insurance type were identified between the PCC and non-PCC groups. Efforts should thus be taken to identify and remove barriers to accessing prenatal clubfoot information in the hopes of providing more universal prenatal understanding of clubfoot diagnosis and treatment prior to delivery.

# Measuring what Children like or Dislike about their Prosthesis: Development of a New PROM to Measure Children's Satisfaction with their Prosthesis

**Corey Gill, MD, MA,** Harpreet Chhina, PhD, Anne Klassen, PhD, Brittany Pousette, MSc, PhD(Candidate), and Anthony Cooper, FRCSC

#### 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 medical school and orthopaedic residency at Washington University in St. Louis, followed by a Fellowship in Pediatric Orthopaedic Surgery at the Scottish Rite Hospital for Children. 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:** Children with limb deficiencies have unique barriers to participating in day to day activities and in sports and recreational activities (1). Satisfaction with the prosthesis is an important factor in regaining mobility and is important for optimizing the use of the prosthesis, minimizing rejection, and increasing compliance with the medical regimen (2,3). Studies have shown that in general, 40-60% of patients with amputation are not satisfied with their prostheses (4,5). Dissatisfaction with the prosthesis leading to rejection of the prosthesis has been seen in up to 31% of the lower limb amputees(6). Non-use rates of upper limb prostheses among children have been reported to be as high as 50% (7). Hence, providing a prosthesis that children like and are satisfied with can potentially increase the regular use of prostheses in children which can lead to increased participation in activities and can improve their overall health-related quality of life (HRQL). It is important to ensure that satisfaction with prosthesis is assessed directly from a child's perspective using an appropriate measurement instrument. Hence the objective of our study is to develop a patient-reported outcome measure (PROM) to assess satisfaction with prostheses in children with amputations and limb differences.

**Methods:** A prospective multiphase, mixed-methods study is in progress. Phase 1(in-progress) included cognitive debriefing interviews with children between the ages of 8-18 years who use upper limb and lower limb prostheses. Study invitations were sent through the limb reconstruction clinic at BC Children's Hospital, several prosthetic clinics in Canada, the War Amps newsletters and social media. Data were collected on age at the time of interview, gender, biological sex, diagnosis, treatment history including type of amputation, treatment, and stage of treatment at the time of interview.

**Results:** At the time of submission, 7 interviews with children (5 boys, 2 girls) with lower limb prosthesis have been conducted. Mean age of interviewed children was 15.62 years (range 8-17 years). Study is open to recruitment and more interviews will be conducted. Once data saturation is achieved for interviews, the current draft of the prosthesis PROM will be revised.

Analysis of the existing data indicates some minor edits to the current draft of the prosthesis PROM. New themes that emerged from these 7 interviews include flexibility of use across different situations, experience with socks and liners and flexibility, look and durability of the prosthetic foot.

Expert opinion on this draft version will be obtained from the orthopaedic surgeons, prosthetists, nurses, physiotherapists, occupational therapists, and psychologists. This final version will be used in Phase 2 to conduct an international study to collect data from a larger sample of children who use prosthesis, and a quantitative analysis will be conducted to finalise the prosthesis PROM.

**Conclusion:** Measuring children's satisfaction with their prosthesis using a validated PROM is the first step towards improving satisfaction with prosthesis. This is the first study to develop a PROM by directly engaging children with prosthesis during the development and validation of this new PROM.

# The Effects of Orthoses Optimization on Gait Biomechanics and Function in Children with Cerebral Palsy: An Exploratory Study

Teresa Pierce, PT, DPT, PhD, Karl Barner, CPO, Mark Geil, PhD, and Alyssa Fiss, PT, PhD

#### Short Bio of all Presenting Authors

Teresa Long Pierce, PT, DPT, PhD, is a board-certified pediatric clinical specialist and is a faculty/researcher at the Philadelphia College of Osteopathic Medicine Department of Physical Therapy in Suwanee, Georgia (PCOM-GA). She is a graduate of Georgia State University School of Physical Therapy in Atlanta, Georgia, and has extensive experience in physical therapy practice and practice management in a variety of settings. Dr. Pierce has a transitional doctor of physical therapy degree in pediatric science from Rocky Mountain University of Health Professions in Provo, Utah and completed a PhD in Physical Therapy at Texas Woman's University. She is a licensed physical therapist and provides pro bono services in local pediatric clinics.

Dr. Pierce's pediatric research interests include examining participation of children with cerebral palsy (CP) across settings and exploring ankle foot orthoses (AFO) use in ambulatory children with CP. She has led workshops and seminars on a variety of topics, such as, infant/child development, family-centered care, optimizing AFO intervention, and interprofessional collaboration. She is a member of the American Physical Therapy Association's Academy of Pediatric Physical Therapy, the Academy of Physical Therapy Education, and the American Academy of Cerebral Palsy and Developmental Medicine. Dr. Pierce dedicates a large amount of time to professional as well as community service and is an advocate for improving participation and mobility for children with cerebral palsy.

## Abstract

**BACKGROUND & PURPOSE:** Most children with cerebral palsy (CP) will learn to walk; however, gait abnormalities are common and vary based on the severity of upper motor neuron involvement.1,2,3 Ankle foot orthoses (AFOs) are typically prescribed for children with spastic CP.4,5 Many receive standard AFOs with fixed ankles that have an ankle angle of 0 degrees (neutral/ plantigrade) or a few degrees of dorsiflexion.6-9 A standard AFO can be problematic if a child lacks available range of motion in the ankle from short muscle length of the gastrocnemius, as is common with spastic CP.10 Current literature recommends optimizing AFOs using a segmental approach to orthotic prescription that evaluates and accommodates for impairments in body structure/function to optimize function called OSKAR, or Optimal Segmental Kinematic and Alignment Approach to Rehabilitation.11-17 The purpose of this study was to compare biomechanics, function, and client satisfaction when wearing OSKAR AFO-footwear combination (AFOFCs) versus standard AFOFCs in children with CP.

**METHODS:** This study used a cross-sectional, repeated-measures design and included participants with a diagnosis of spastic diplegic CP, Gross Motor Function Classification System levels I-III. Ten children ages 7 to 13 years participated in the study and 7 of the ten were male. Participants were assessed and two pair of AFOFCs were fabricated for each participant—one standard pair of AFOFCs and one pair designed using the OSKAR method for orthotic prescription. Instrumented 3D gait analysis was used to collect biomechanical gait data when wearing OSKAR AFOFCs and standard AFOFCs. Additionally, three functional outcome measures were performed including the Pediatric Balance Scale (pbs), Standardized Walking Obstacle Course (SWOC), and Six-minute Walk Test (6MWT). Client satisfaction with each brace condition was assessed using the Orthotic and Prosthetic User Survey (OPUS). Descriptive statistics were determined for all dependent variables. Due to the small number of participants and several normality violations in the data, non-parametric analyses were performed using the Wilcoxon signed-rank test.

**RESULTS**: Peak knee extension improved in OSKAR AFOFCs; however, values were not significantly different between the two orthotic conditions. Balance scores were significantly higher when wearing the OSKAR AFOFCs – all other functional scores were comparable between conditions and there were no significant differences in satisfaction scores (see Figure 1).

Variables	Media Standard AFOFC	an OSKAR AFOI	T FC	z	р	r
<i>n</i> = 8						
Peak KE	-0.95	0.55	23.00	0.70	0.484	0.73
<i>n</i> = 10						
PBS	47.00	50.50	26.50	2.12	<mark>0.034*</mark>	0.95
SWOC	16.63	15.81	9.00	9.81	0.059	0.90
6MWT	291.55	298.56	25.00	-0.26	0.799	0.94
OPUS	28.00	29.50	30.50	1.77	0.077	0.84

Key: KE=Knee Extension; OPUS=Orthotic & Prosthetic User Survey; PBS=Pediatric Balance Scale; SWOC=Standardized Walking Obstacle Course; 6MWT=Six- Minute Walk Test

Figure 1. Summary of Findings.

**DISCUSSION:** Similar to findings in previous research,13 balance scores significantly improved in the OSKAR condition. There was also a trend towards peak knee extension values that were closer to typical when wearing OSKAR AFOFCs, particularly in children with hyperextended gait patterns. This study provides preliminary data for larger future studies and longitudinal designs are needed to explore changes in biomechanics and function over time.

**CONSLUSION:** Improved balance could provide greater independence with self-care, participation in home/school activities, and community involvement.

**CLINICAL APPLICATIONS:** Results from this study could inform clinical decisions regarding orthotic prescriptions and positively impact AFO interventions for ambulatory children with CP.

# **Enhancing Scoliosis Brace Comfort – The Key Role of Orthotists**

Megan Glahn Castille, MS, CPO, and Kayli Schwantz, BS

## Short Bio of all Presenting Authors

Kayli Schwantz is a board eligible prosthetist orthotist currently working at Methodist Rehabilitation Orthotics and Prosthetics in Flowood, MS. The work she is presenting was her master's thesis completed during her time at Baylor College of Medicine in Houston, TX. She received her B.S. Exercise Science from Arkansas State University and is originally from eastern Arkansas. Her interests include lower extremity prosthetics, scoliosis management, pediatrics, and mastectomy care.

## Abstract

**Introduction:** While scoliosis bracing is an effective method for controlling curve progression, adherence is often challenging and multifactorial, with both physical and psychosocial components. Since braces must be worn for many hours each day, brace comfort frequently appears in the literature, and superior brace comfort has been suggested to improve brace acceptance. Despite the importance of comfort, it is unclear what factors are associated with brace comfort.

**Objective:** The purpose of this study was to identify factors associated with brace comfort in order to better understand the patient experience and improve care.

Study Design: This study consisted of a cross-sectional survey.

**Methods:** The survey included the BSSQ-Brace and questions about demographics, diagnosis, bracing appointments, comfort, and overall experience. It was distributed via the Scolios-us website, social media, and email newsletter from January to August 2023. Subjects were eligible to participate if they had a scoliosis diagnosis and were currently wearing a scoliosis brace. Descriptive statistics, Mann-Whitney U tests, and Kendall's tau-b correlations were used to analyze responses.

**Results:** Fifty-one subjects with a median age of 13.5 (IQR: 3) participated in the study. Subjects reported that brace comfort/discomfort (41%) is the biggest barrier to brace adherence, followed by extracurricular activities (29%), peer pressure (10%), brace appearance (6%), and bullying (2%). Orthotist gender emerged as a key factor, with significant positive associations between women orthotists and brace comfort at the fitting appointment (U = 159.5, p = .002) (Figure 1), ease of adjusting to the brace (U = 192.5, p = .015), and skin integrity (U = 190.0, p = .013). Brace comfort at fitting was correlated to ease of adjusting to the brace ( $\tau b = .420$ , p < .001). Brace pain at the fitting (U = 91.5, p = .014) and current brace pain (U = 81.0, p = .046) were negatively associated with BSSQ-Brace scores, while perceived brace appearance and BSSQ-Brace scores were positively correlated ( $\tau b = .339$ , p = .002). The orthotists' understanding of subjects' needs emerged as another key factor, demonstrated by strong correlations with perceived brace fit ( $\tau b = .515$ , p < .001), perceived orthotist skill level ( $\tau b = .660$ , p < .001), and desire to choose the same orthotist again ( $\tau b = .571$ , p < .001). Brace type was not found to be associated with brace comfort, ease of adjusting, or BSSQ-Brace scores.

**Conclusions and Significance:** Brace comfort appears to be linked to the orthotist, not the brace design. Women orthotists are associated with superior brace comfort at the fitting appointment. Since brace pain and poor brace appearance are associated with increased brace-related stress, orthotists should focus on these details during fitting and follow-up appointments. Finally, orthotists should actively listen and understand patients' needs to improve patients' bracing experience.



Figure 1: Perceived brace comfort at the end of the fitting appointment, with 1 representing "very uncomfortable" and 5 representing "very comfortable."

# Feasibility of a Randomized Controlled Trial on Cranial Orthosis Therapy for Severe Deformational Plagiocephaly: A Pilot Study

Pegah Amir Yazdani, MD, Rasha Alhaeik, BSc, Alexander G. Weil, MD, FRCSC, and Camille Costa, MDCM, MSc, BSc

## Short Bio of all Presenting Authors

Dr. Pegah Amir-Yazdani completed her medical degree at University of Sherbrooke in Canada. She is currently in her final year of residency in Physical Medicine and Rehabilitation (Physiatry) at the University of Montreal.

Dr. Camille Costa first obtained a degree in physiotherapy from McGill University. She then completed her medical degree at McGill University. She went on to complete her residency in Physical Medicine and Rehabilitation (Physiatry) at the University of Montreal, followed by a subspecialty in Pediatric Physiatry at CHU Sainte-Justine. She also completed a master's degree in Biomedical Sciences at the University of Montreal. She currently works at Shriners Hospital for Children – Canada, Sainte-Justine Hospital, and their affiliated rehabilitation centers, where she sees children with neuromusculoskeletal issues.

#### Abstract

#### Background:

Deformational plagiocephaly (DP) is a common asymmetric head deformity in infants. Cranial orthosis therapy is frequently prescribed to treat severe cases, yet robust evidence supporting its efficacy remains limited (1). The first randomized controlled trial (RCT) on cranial orthosis therapy, published in 2014 as part of the HEADS trial, found no meaningful impact of helmets compared to natural evolution (2). However, this study excluded premature infants, those with torticollis, and patients with very severe deformations — populations that constitute a large proportion of those treated for DP (1).

#### **Objective:**

This pilot study aimed to assess the feasibility of conducting a RCT on the efficacy of cranial orthosis therapy for severe DP in infants aged 4 to 7 months.

#### Methods:

This prospective randomized controlled pilot study was conducted at CHU Sainte-Justine, a pediatric hospital, between December 2023 and September 2024. Infants aged 4 to 7 months with severe DP were randomized 1:1 to receive cranial orthosis therapy within 1 week (intervention group) or 7 weeks later (control group, representing the natural course). The 7-week delay reflected institutional wait times. Allocation was concealed, and custom cranial orthoses were fabricated based on 3D-scans and worn ≥20 hours/day. Follow-ups occurred at 6 and 12 weeks. Outcome assessors were blinded. Feasibility metrics included recruitment, adherence to timelines, loss to follow-up, caregiver acceptability, and side effects. Descriptive analysis was conducted for effectiveness outcomes (CVA, CVAI, ODDI, CI) and parental satisfaction.

#### **Results:**

Twenty-four patients were recruited over six months. Recruitment was prolonged because of restrictive inclusion criteria. One family randomized to the control group withdrew and sought earlier orthosis fabrication at a private clinic.

Logistical barriers included coordinating orthotist and physician appointments. Helmet deliveries occurred on the planned date for 30% of participants, and within 1 week for 74%. At the 6-week follow-up, 65% of participants were seen by orthotists within 1 week of the planned date. At 12 weeks, 57% saw their orthotist and 56% saw their physician within 1 week of planned date, but only 7 patients were seen by both on the same day.

Randomization was largely successful, though one early helmet delivery (42 days early) raised concerns about randomization application. Caregiver-reported acceptability was high, with a mean satisfaction score of 4.34 (±0.65) (5-point scale), and all caregivers indicated they would repeat the therapy. Minor side effects were reported, including sweating (65%), helmet odor (65%), and mild skin irritation (56%), primarily when helmets required adjustments.

## **Conclusion:**

This pilot study demonstrates the feasibility of conducting a RCT on cranial orthosis therapy while identifying areas for improvement. Recruitment strategies and logistical coordination require optimization to enhance adherence to planned timelines. Employing a dedicated research coordinator could address challenges in coordinating appointments and recruitment.

These findings will inform the design of a future RCT aimed at establishing the efficacy of cranial orthosis therapy in treating severe deformational plagiocephaly.

# Parent Satisfaction and Post-Treatment Changes at 18 Months of Age After Cranial Remolding Treatment

## Steven Slawinski, CO, LO, FAAOP

#### Short Bio of all Presenting Authors

Steven Slawinski CO LO FAAOP is a graduate of Northwestern University's Prosthetic and Orthotic Center. He is certified through the American Board for Certification in Orthotics and Prosthetics and licensed in the states of New Jersey and Pennsylvania. He is the current Director for OrthoPediatrics Specialty Bracing's Cranial program and focuses on training, research, and program development.

#### Abstract

#### INTRODUCTION

Current literature shows that heads affected by flattening will continue to improve post-treatment, as the child ages. It has also been found that parents are less concerned with head shape as their child ages. The purpose of this study is to review parent satisfaction and changes in head shape of our patients treated with cranial remolding orthoses during a follow-up visit at 18 months of age.

#### METHOD

Subjects: Sixty-seven patients who underwent cranial remolding treatment and returned at 18 months of age

Apparatus: Three-dimensional surface tomography scans were acquired using a Polhemus FastScan Handheld Class I Laser Scanner (Polhemus, Vermont, United States) or a Bodyscan White Light Scanner (Techmed, Quebec, Canada). The images were processed using Rodin4DScan software (Rodin 4D, Merignac, France) or M4DSoft software (Quebec, Canada) to create a solid object and align the model.

Procedures: The scans were exported to the Rodin4D Neo or kept in M4DSoft software to measure head circumference, cranial width, cranial length, cranial index, cranial vault asymmetry, and cranial vault asymmetry index. A custom survey was filled out by the parent during the visit at 18 months of age.

Data Analysis: Survey results were compiled and scan data from the visit at 18 months of age was compared to the scan data taken during the patients' treatment discharge.

#### RESULTS

Sixty-seven patients returned at 18 months of age and completed the custom survey. 4 of the parents did not identify their child in the survey, and 24 others were missing scan data, leaving 39 that were included in the reported data. The cephalic index (CI) of patients decreased an average of 2.4% (with a range of 4.4% increase to 7.2% decrease). The cranial vault asymmetry (CVA) increased an average of .57 mm (with a range of 5 mm increase to 2.5 mm decrease). The cranial vault asymmetry index increased by a median of .18% (with a range of 3.45% increase to 1.81% decrease).

Only 1 survey respondent reported that they were "somewhat dissatisfied" with their child's head shape at the end of treatment, and no respondents indicated they were "very dissatisfied" with their child's head shape at the end of treatment OR at the 18-month visit. 100% of respondents stated they would recommend treatment to others, and 94% stated they would make the same decision to pursue treatment (the 4 others did not respond to the question).

#### DISCUSSION

Future work is needed to compare volumetric data from the end of treatment to 18 months of age. Further investigation is needed to identify why some patients' CVA increased, while others decreased.

#### CONCLUSION

From the time of discharging patients from treatment to 18 months of age, cephalic index was shown to decrease, as expected, while CVA and CVAI increased, albeit, only by .57 mm and .18%, respectively. Only one parent reported that they were dissatisfied with their child's head shape at either the end of treatment or at 18 months of age, so this reinforced the efficacy of our program standards.

#### **CLINICAL APPLICATIONS**

Based on survey open-ended responses, initiating treatment at an earlier age was a common request from parents, which should be communicated to referral sources.

# 2D and 3D Changes of Deformational Head Shapes during Repositioning Therapy and Cranial Remolding Treatment

Tiffany Graham, C/LPO, FAAOP(D), Jijia Wang, PhD, Fabian A. Calderon, MPO Student, and Rami Hallac, PhD

#### Short Bio of all Presenting Authors

Tiffany Graham, MSPO, C/LPO, FAAOP(D) is an Associate Professor at the University of Texas Southwestern Medical Center in Dallas. She received her bachelor's degree in Engineering Science from Trinity University and her master's degree from the Georgia Institute of Technology. She is the American Academy of Orthotists and Prosthetists' Vice President and Immediate Past Chair of the Academy's Research Council. Tiffany's clinical career has been focused on pediatrics and she has specialized in Cranial Remolding for the past 15 years. In addition to having multiple peerreviewed published manuscripts, she is a three-time recipient of the Thranhardt Award and the 2025 Tamarak Award.

#### Abstract

#### Introduction:

Deformational head shapes (DHS) such as plagiocephaly (DP), brachycephaly (DB), and asymmetrical brachycephaly (DAB) are often treated with Repositioning Therapy (RT) or a Cranial Remolding Orthosis (CRO)1. The treatment decision is typically made using either a visual assessment2 or 2D measurements of the skull3. However, 2D measurements do not always accurately portray a 3D shape3-4. 3D measurements are rarely used, but there is a growing interest3-4. In this pilot study, infants with DHS were measured and compared in both 2D and 3D as they underwent treatment.

#### Methods:

This study was approved by the UTSW IRB and caregivers consented to participation. Subjects included 34 infants (20 male, 14 female) who were diagnosed with a DHS. 2D and 3D measurements collected include the Cranial Vault Asymmetry Index (CVAI) and the Cephalic Index (CI). Each DHS was defined as follows: DP: CI<90% and CVAI>3.5; DB: CI>90% and CVAI>3.5. Each RT subject was enrolled in the study at 2 months of age. Infants in the CRO group were enrolled at 4-6 months of age. 3D measurements were acquired using the 3dMD scanning system which uses anatomical landmarks tailored to each subject's head shape. 2D measurements were acquired using the SmartSoc or STARscanner (supplemented by orthotist caliper measurements when scan measurements in the RT and CRO groups for each DHS. A Mann-Whitney U Test was performed for each comparison to test for statistical significance.

#### **Results and Discussion:**



Figure 1: Box plot demonstrating the 2D changes in CVAI across 12 DP, 14 DAB, and 8 DB subjects.



Figure 2: Box plot demonstrating the 2D changes in CI across 12 DP, 14 DAB, and 8 DB subjects.



Figure 3: Box plot demonstrating the 3D changes in CVAI across 12 DP, 14 DAB, and 8 DB subjects.



Figure 4: Box plot demonstrating the 3D changes in CI across 12 DP, 14 DAB, and 8 DB subjects.

	Head Shape Type					
	DP		DAB		DB	
	RT	CRO	RT	CRO	RT	CRO
Count (n)	6	6	6	8	6	2
Mean Starting Age (weeks) ± SD	10.50 ± 0.79	22.48 ± 3.39	8.83 ± 2.97	22.14 ± 4.58	10.64 ± 1.79	22.21 ± 8.59
Mean Treatment Duration (weeks) ± SD	18.57 ± 12.50	17.79 ± 7.73	25.19 ± 12.78	22.34 ± 5.33	29.05 ± 16.95	26.36 ± 1.72

**Table 1:** Table displaying the demographics of the participating subjects for each deformational head shape. The count,age at treatment initiation (average and SD), and the treatment duration time (average and SD) are included for eachtreatment modality per head shape.

2D analyses demonstrated CVAI mean change was greater in all DHSs with use of a CRO (Figure 1) and on average, changed at a faster rate in the DP and DB groups that RT subjects. Treatment of all DHSs with a CRO displayed a greater mean correction (Figure 2) and rate of correction for 2dCI, but was not statistically significant.

3D analyses showed CROs were superior in correcting 3dCVAI in the DAB and DB groups (Figure 3) and CRO treatment more effectively corrected CI for patients diagnosed with DAB (Figure 4) which was statistically significant. 3dCI had greater mean changes in the CRO group for DB and DP; however, these results were not statistically significant.

The lack of statistical significance is likely due to a low number of subjects. An increase in the number of subjects may yield statistically significant results following the observed trend in the literature regarding CRO treatment achieving greater rates of cranial correction than RT1.

#### **Conclusion:**

Usage of a CRO generally demonstrated clinically superior 2D results at a faster rate than RT in correcting targeted cranial measurements across DHSs, despite CRO infants receiving treatment at an older age. Further 3D analyses are warranted but did show CROs have superior 3dCl correction.

#### Acknowledgements:

This work was supported by an AOPA Research Award administered by the Center for Orthotics and Prosthetics Learning and Outcomes/Evidence based Practice.

# **Cranial Remolding Orthosis Treatment for Pansynostosis and Cloverleaf Skull**

## Kaitlin Rivest, MSPO, CPO

#### Short Bio of all Presenting Authors

Kaitlin Rivest is a Certified Prosthetist Orthotist at Boston Children's Hospital and the Assistant Resident Director for OPSB/Boston O&P. She is passionate about patient care, utilizing a multidisciplinary approach to foster strong relationships and achieve improved patient outcomes. Valuing lifelong learning, Kaitlin takes pride in mentoring residents and is committed to their education, ensuring ethical practice and upholding clinical standards for superior results.

#### Abstract

Background Cranial Remolding Orthosis (CRO) treatment for rare cranial malformations like pansynostosis and cloverleaf skull is under-documented. Cloverleaf skull is a severe cranial deformity caused by the premature fusion of cranial sutures, leading to a characteristic "cloverleaf" shape. If left untreated, this condition can result in increased intracranial pressure and developmental complications. This case study focuses on the application of CRO therapy in a seven-week-old female diagnosed with pansynostosis and cloverleaf skull at Boston Children's Hospital.

Case Description The patient underwent an extensive craniectomy and cranial vault remodeling to address the pansynostosis and associated cranial deformity. Following surgery, the patient was prescribed a custom CRO to facilitate cranial growth and remodeling. The CRO was fabricated using three-dimensional surface scans, with CAD modifications made to ensure proper accommodation of postoperative cranial growth.

Treatment and Outcomes Over the course of 31 weeks of CRO treatment, the patient exhibited significant improvements in cranial shape. The cephalic index, a key measurement of cranial proportion, decreased from 105% to 87%. Additionally, there was a 60mm increase in cranial circumference. The most pronounced improvements occurred within the first few weeks of therapy, a result enhanced by the family's excellent compliance with the prescribed CRO wear schedule. Due to the patient's rapid growth and evolving cranial shape, three different CROs were utilized throughout the treatment period. Each CRO required unique adjustments to accommodate surgical site complications, manage bony overgrowth at the patient's occipital bone, and address recurring skin irritation.

Discussion This case underscores the critical role of a multidisciplinary approach involving plastic surgery, neurosurgery, and orthotists. Despite the rarity of conditions like pansynostosis and cloverleaf skull, this case highlights how CRO therapy can be an essential adjunct to surgical interventions, promoting symmetrical cranial growth and enhancing surgical outcomes.

Conclusion CRO therapy, when applied in a coordinated, multidisciplinary care setting, can achieve successful outcomes for complex cranial deformities such as pansynostosis and cloverleaf skull. This case

contributes valuable clinical data to the limited body of literature on CRO effectiveness in treating rare cranial malformations and reinforces the orthotist's vital role in such complex cases.

Implications for Practice Presenting this case at ACPOC would offer insights into a seldom-seen condition, highlighting the successful use of CRO in conjunction with surgical interventions. It emphasizes the importance of a collaborative approach to managing rare cranial malformations and provides data to support the effectiveness of CRO therapy in these complex scenarios.



CT scan showing multiple coronal erosions in the superior skull



Surgical site after the open craniectomy with extensive bone removal and cranial vault remodeling



Post operative cranial comparison report generated after each scan to track changes throughout the process

# Developmental Outcomes of School-Aged Children Diagnosed with Positional Plagiocephaly/Brachycephaly in Infancy

**Caroline Zeiser, MSPO, CPO**, James Wynne, CPO, Michele DeGrazia, PhD, RN, NNP-BC, FAAN, Alexandra Cole, MPH, Laura Berbert, MS

## Short Bio of all Presenting Authors

Caroline Zeiser is a Certified Prosthetist Orthotist with OPSB/Boston O&P out of Weymouth, MA. She previously completed her residency with Boston O&P, including rotations at several Boston Children's Hospital locations. Her clinical interests include cranial remolding, scoliosis and pediatric prosthetics.

## Abstract

#### Introduction

Positional plagiocephaly/brachycephaly (PPB) is a common problem in infancy. There are several treatment options for PPB, including observation, repositioning, physical therapy, or a cranial remolding orthosis (CRO). A CRO is designed to re-direct head growth to areas of asymmetry or flattening. Many parents will choose CRO due to concern for the child's appearance, as well as guidance from their provider. As providers, it is important to be knowledgeable of the short- and long-term outcomes of PPB to educate families on treatment options, ensuring informed decisions. The purpose of this study is to investigate the developmental outcomes of children 4-10 years old, diagnosed with PPB during infancy. Socio-demographic, social, medical, and developmental outcomes were compared across three treatment groups, those: 1. treated with a CRO and were formally discharged (treatment), 2. treated with a CRO, did not complete treatment, and self-discharged (partial treatment), and 3. not treated with a CRO (no treatment).

#### <u>Methods</u>

In this descriptive cohort study, a questionnaire was created by the investigators to elicit parent reports of their child's development, following a diagnosis of PPB in infancy. A total of 3,935 children and their parents were identified through an Electronic Medical Record query as having been evaluated for a CRO in a Boston Orthotic & Prosthetic Boston area clinic from April 1, 2011, to June 25, 2019. Parents were sent the questionnaire via email and indicated their consent prior to completing the questionnaire. The additional collection of data included head measurements, PPB classifications, and treatment decision. Of the 217 (5.5%) respondents, 206 participants were included in the final sample. Data were analyzed using descriptive and comparative statistics to examine differences across treatment groups and PPB severity.

#### <u>Results</u>

Almost all of the parents whose child received a CRO (93.4%) reported being satisfied with treatment. About half of the participants (48.5%) reported their child with PPB needed at least one developmental intervention, however there were no associations with study group assignment. Children with higher levels of occupational therapy (p=0.116) and early intervention (p=0.165), as well as significantly higher levels of individualized education plans (p=0.046) and special attention or help in school (p<0.001) were observed in the low severity brachycephaly group, as compared to the high severity group. Furthermore , it is important to note that 100% of participants reported their child was not bullied, and 99.5% reported their child was not teased because of PPB.

## Discussion

There are two notable discussion points from this study. The first is that many children with PPB required at least one developmental intervention. This finding supports past studies showing associations between PPB and developmental outcomes and reaffirms the need to follow these children closely to ensure they are meeting their developmental milestones. The second finding to note is that PPB is a complex phenomenon with differing outcomes based on severity, location, and treatment. This finding suggests that more research is needed to better understand the impact of PPB and to provide parents with evidence-based guidance as they make their treatment decisions.

# Types and Frequencies of Femoral, Hip, and Pelvic Anomalies Associated with Tibial Deficiency and Implications on Treatment

Alyssa Barre, MD, Grace Markowski, BS, David Westberry, MD, Kenneth Powell, MD and Janet Walker, MD

## Short Bio of all Presenting Authors

Alyssa is a PGY-3 Orthopaedic Surgery Resident at the University of Kentucky planning to pursue pediatric orthopaedics with a special interest in limb deformity and skeletal dysplasia.

## Abstract

#### Introduction

Tibial deficiency (TD) is a rare congenital anomaly, occurring in approximately 1 in 1 million live births, characterized by a shortened or absent tibia. Previous studies indicate that 60-75% of TD patients present with additional limb and organ system anomalies, particularly affecting the upper extremities, spine, and viscera. Femoral and hip anomalies have been reported 25% of cases. Treatment strategies for TD include orthotics, amputations, and limb reconstructions; thus, the presence of ipsilateral lower extremity anomalies significantly influences therapeutic approaches. This study aims to characterize femoral, hip, and pelvic anomalies associated with TD and assess their impact on treatment outcomes within a cohort of over 650 tibial deficient limbs.

#### Methods

A retrospective review was conducted on TD patients treated at seven tertiary pediatric orthopaedic facilities from 2004 to 2022. Patients were retrospectively identified by diagnosis code query, and charts and radiographs were analyzed to gather demographic data, radiographic findings, and all noted anomalies. Patients lacking sufficient data were excluded.

#### Results

A total of 491 patients with 650 tibial deficient limbs were analyzed. The average age of the cohort at last visit was 10.3 years (range 0.02-23.2 years). Among them, 121 (19%) exhibited femoral, hip, or pelvic anomalies. Femoral anomalies were the most prevalent (13%), followed by hip anomalies (8%) and pelvic anomalies (<1%). Treatment modifications due to ipsilateral anomalies were observed in 10% of TD limbs (n=61).

#### Femoral Anomalies

Eighty-four limbs (13%) had femoral anomalies, with congenital femoral deficiency (6%, n=39) being the most common. Other anomalies included femoral shaft duplication (4%, n=25, distal femoral duplication (2%, n=12), wide distal femur, asymmetric distal femoral ossification, hemi-condyle deficiency, and congenital knee fusion in flexion (<1% each, n=2 each). Approximately 46% of limbs with femoral anomalies had altered treatment courses, necessitating interventions such as excisions, knee fusions, and adjustments in prosthetic design.

#### Hip Anomalies

Fifty limbs (8%) presented with hip anomalies, primarily femoral head dislocation (n=28). Treatment alterations occurred in 36% of these cases, including surgical reductions and proximal femoral and pelvic osteotomies.

#### Pelvic Anomalies

Only six limbs (<1%) had pelvic anomalies, consisting of three superior pubic rami (SPR) and ilium deficiencies, two persistent SPR synchondroses, and one duplicated ischium. There were no resultant changes in treatment protocols for pelvic anomalies.

#### Conclusion

This study highlights the significant impact of associated femoral and hip anomalies on treatment for patients with tibial deficiency. Nearly 10% of the analyzed limbs required modifications in management due to these anomalies, including surgical interventions and differing prostheses. The findings emphasize the need for thorough preoperative assessments to tailor treatment strategies effectively. These insights reinforce the value of a multidisciplinary approach in managing congenital limb deficiencies, ensuring that all aspects of a patient's condition are considered in the treatment plan.

# In-Brace Radiographs and not Coronal Deformity Angular Ratio Independently Predicts Curve Progression in Providence Nighttime Brace Treatment for Idiopathic Scoliosis

**Regina Velarde, MS, BS**, Martin Heegaard, PhD, MD, Amy L. McIntosh, MD, Megan E. Johnson, MD, and Soren Ohrt-Nissen, PhD, MD

#### Short Bio of all Presenting Authors

Regina Velarde is a second-year medical student at UT Southwestern. She received a Bachelor of Science in Biomedical Engineering and a Master of Science in Medical Physiology, both from Case Western Reserve University. Her research interests include pediatric orthopedic surgery, particularly scoliosis. She has been working on multiple scoliosis research projects with Scottish Rite for Children.

#### Abstract

Introduction: The rigidity of the thoracic spine has raised concerns regarding the efficacy of night-time bracing (NTB) for thoracic curves in adolescent idiopathic scoliosis (AIS). However, some studies suggest that NTB may yield outcomes comparable to full-time thoracolumbar sacral orthosis (FTB). This study aims to compare the initial in-brace correction percentage (IBC%) and final curve progression between NTB and FTB in AIS patients with thoracic curves.

Methods: In a dual center setting, we retrospectively included skeletally immature AIS patients with thoracic curves measuring 20-45°, treated with either NTB or FTB. Patients with significant compliance issues were excluded (NTB: early brace discontinuation; FTB: <6 hours of daily wear). Propensity-score matching was conducted for gender, Risser stage, age, and curve size at brace initiation. Radiographic parameters were measured at the beginning and end of brace treatment, with in-brace radiographs obtained at brace fitting. A univariate linear regression analysis was used to determine the significance of IBC% on major curve progression.

Results: Among 447 eligible patients, 87 were matched in the NTB group and 134 in the FTB group. Night-time braced patients had significantly higher rates of curve progression (>5° and >50°) compared to FTB patients (60% vs. 33%, p<0.001; 35% vs. 19%, p=0.008). The IBC% was significantly higher in the NTB group compared to the FTB group (59% vs. 37%, p<0.001). In the NTB group, the IBC% did not significantly impact the progression of the major Cobb angle (Coefficient -0.08, 95%CI -0.24;0.08). In contrast, for the FTB group, a 1% increase in IBC% was associated with a 0.22° decrease in major Cobb angle (Coefficient -0.22, 95%CI -0.30;-0.14).

Conclusion: The NTB demonstrated higher IBC% but also higher progression rates compared to FTB in AIS patients with thoracic curves. The IBC% did not significantly influence progression in the NTB group. However, in the FTB group, an increase in IBC% was associated with a reduction in major Cobb angle.

Significance/Take Home Message: While NTB demonstrated a higher IBC% than FTB, it also resulted in higher progression rates. Future studies should focus on identifying the optimal application of NTB in the management of thoracic curves in AIS patients.


# Night-time vs. full-time bracing in thoracic AIS – Are there differences in curve progression when matching for time-in-brace?

**Regina Velarde, MS, BS,** Martin Heegaard, PhD, MD, Amy L. McIntosh, MD, Megan E. Johnson, MD, and Soren Ohrt-Nissen, PhD, MD

## Short Bio of all Presenting Authors

Regina Velarde is a second-year medical student at UT Southwestern. She received a Bachelor of Science in Biomedical Engineering and a Master of Science in Medical Physiology, both from Case Western Reserve University. Her research interests include pediatric orthopedic surgery, particularly scoliosis. She has been working on multiple scoliosis research projects with Scottish Rite for Children.

## Abstract

Introduction: The full-time thoracolumbar sacral orthosis (FTB) treatment for thoracic adolescent idiopathic scoliosis (AIS) is well-established, but compliance remains a substantial issue. The night-time brace (NTB) with a higher in-brace correction presents a viable treatment option. Whether patients with low compliance in FTB would benefit from switching to an NTB is unknown. This study aimed to compare the efficacy of FTB and NTB in patients with similar brace wear time.

Methods: In a retrospective dual center setting, we included skeletally immature AIS patients with thoracic curves of 20-45°, treated with either FTB or NTB. Patients with compliance ranging between 6-10 hours per day, Risser stage 0-3, and less than one-year post-menarche were included. Radiographic measurements were collected at brace initiation and termination. A mixed effects model was used to determine significant predictors of curve progression >5°.

Results: A total of 80 FTB patients and 106 NTB patients were included in the final analysis. At baseline, the FTB patients were younger (12.4y vs. 13.1y, p<0.001) and had smaller curves ( $31\pm6^{\circ}$  vs.  $37\pm6^{\circ}$ , p=<0.001). The FTB patients showed significantly lower rates of curve progression >5° (44% vs. 63%, p=0.008) as well as progression to >50° (18% vs. 41%, p<0.001). The in-brace correction percentage was 59% ( $\pm18$ ) in the NTB group and 37% ( $\pm18$ ) in the FTB group (p<0.001). In the mixed effects model, we found decreased odds of progression >5° for treatment with FTB (OR 0.30, 95%CI 0.13-0.72), Risser stage 3 (OR 0.23, 95%CI 0.06-0.86), and age (OR 0.67, 95%CI 0.48-0.94). The NTB, male gender, and initial major curve size were associated with increased odds of progression (NTB: OR 3.33, 95%CI 1.39-8.03; Male: OR 5.49, 95%CI 1.62-18.68; Initial curve: OR 1.07, 95%CI 1.01-1.13).

Conclusion: The FTB demonstrated lower progression rates than the NTB in thoracic AIS patients with similar brace wear times. The NTB may play a role in low-risk patients with smaller curves and higher skeletal maturity.

Significance/Take Home Message: The FTB showed less curve progression compared to the NTB, even when matching for brace wear time.

Level of Evidence: III



# In-Brace Radiographs and not Coronal Deformity Angular Ratio Independently Predicts Curve Progression in Providence Nighttime Brace Treatment for Idiopathic Scoliosis

Karina Zapata, PT, DPT, PhD, Dan Sucato, MD, MS, **Kara Davis, CPO, LPO,** MS, Chan-Hee Jo, MD, and Megan Johnson, MD

## Short Bio of all Presenting Authors

Kara Davis & Karina Zapata have been employed by Scottish Rite for Children since 2007, where Kara is the Clinical Coordinator of the Orthotics Department and Karina is a Senior Clinical Scientist.

Kara Davis earned her undergraduate degree from the University of Michigan and her graduate degree in O&P from Eastern Michigan University in 2007. She is recognized as a Fellow with Distinction, and has served as Chair and secretary of the Spinal Orthotics Society, both within the American Academy of Orthotists and Prosthetists. She specializes in scoliosis care at Scottish Rite.

Karina Zapata earned her Doctorate of Physical Therapy at University of Southern California in 2007 and completed her Ph.D. at Texas Woman's University in 2013. She is also Assistant Professor at the University of Texas Southwestern. She loves the transdisciplinary environment at Scottish Rite, and now focuses on research relating to the spine.

## Abstract

**Introduction**: The relationship between in-brace correction (IBC) and C-DAR (coronal deformity angular ratio) with brace treatment outcomes in idiopathic scoliosis utilizing Providence nighttime brace treatment is unknown. We determined 1) whether IBC and C-DAR differ by major curve location, and 2) whether IBC & C-DAR predict curve progression after adjusting for possible confounding variables.

**Methods**: 284 children (56 boys, 228 girls) with idiopathic scoliosis ages 10-16 years, Risser stages 0-2, major curves 15°-40° treated with Providence nighttime braces with IB radiographs were retrospectively reviewed until skeletal maturity or surgery. IBC was calculated by comparing curve magnitude differences between the standing brace prescription radiograph and supine IB radiograph 2 months later. C-DAR was calculated by a single rater who divided the number of vertebrae of the primary curve from the curve magnitude; larger values indicate shorter, sharper curves. Major curve location (thoracic, thoracolumbar [TL], or lumbar [L]) was defined by the primary curve apex location.

**Results**: IBC of the primary curve averaged  $103\%\pm29\%$  (n=282) and secondary curve averaged  $72\%\pm29\%$  (n=144). TL curves had higher IBC than L and thoracic (113% vs. 94% vs. 88%, p<0.001). L curves had higher C-DARs than TL and thoracic (4.6 vs. 4.2 vs. 3.3, p<0.001). IBC was inversely associated with curve progression (r=-0.33, p<0.001), C-DAR (r=-0.27, p<0.001), curve magnitude (r=-0.18, p=0.002), and body mass index (BMI), [r=-0.12, p=0.041]). C-DAR was associated with curve magnitude (r=0.66, p<0.001), age (r=0.22, p<0.001), Risser stage (r=0.15, p=0.013), and curve progression (r=0.13, p=0.02). Multivariate regression analysis adjusting for age, biologic sex, BMI, triradiate cartilage (TRC) status, curve magnitude, and Risser stage revealed that decreased IBC (OR 0.98, 95% CI 0.97-0.99) and C-DAR (OR 1.35, 95% CI 1.03-1.77) were still associated with curve progression  $\geq$ 6°, in addition to open TRC status (OR 2.41, 95% CI 1.22-4.91). Each additional increase of 1% IBC was associated with a 2% decreased odds of curve progression  $\geq$ 6°.

**Conclusion**: TL curves have the highest IBC, likely due to thicker brace pads. L curves have higher C-DAR, likely due to less vertebrae involved. Both IBC and C-DAR are independent predictors of curve progression in Providence nighttime bracing.

**Significance:** Optimizing IBC is an important factor for successful Providence brace treatment outcomes for idiopathic scoliosis and should be evaluated after brace delivery. Determining a child's C-DAR at brace initiation can help educate families about curve progression risk.

# Successful Nighttime Brace Treatment Modulates Growth in Children with Idiopathic Scoliosis

Karina Zapata, PT, DPT, PhD, Joshua Utay, EdD, CPO, LPO, Katherine Beard, BS, Dan Sucato, MD, MS, and Megan Johnson, MD

## Short Bio of all Presenting Authors

Dr. Karina Zapata has a Doctorate of Physical Therapy from University of Southern California (2007) and Ph.D. from Texas Woman's University (2013). She is a Senior Clinical Scientist at Scottish Rite for Children. She is also Assistant Professor at the University of Texas Southwestern.

Katherine Beard recently graduated from Baylor University with a Bachelors of Science in Bioinformatics. Currently working as a Clinical Orthopedic Research Assistant at Scottish Rite for Children, she plans to attend graduate school.

## Abstract

Introduction: Studies show that some curves improve with brace wear, especially in younger patients with smaller curves. The mechanism behind this is unclear; however, one explanation for this improvement could be growth modulation of the vertebrae during brace wear. The goal of this study was to determine: 1) if curves that improve  $\geq 6^{\circ}$  during brace treatment show evidence of growth modulation through improvement in concave versus convex symmetry and 2) if curves that progress  $\geq 6^{\circ}$  fail to modulate or show asymmetric growth.

Methods: Patients who completed nighttime brace treatment starting at Risser 0 for idiopathic scoliosis with 2-year follow-up were retrospectively reviewed. Improved and progressive groups were matched for age (11.7±1.3 years), sex (81% girls), curve location/magnitude (86% thoracolumbar/lumbar curves 22.9°±2.4° pre-brace), triradiate cartilage (69% open), brace adherence (7.6±1.8 hrs/night), and growth (13.4±6.1 cm). All measurements were made pre-brace, inbrace, and post-brace. Vertebral body heights and wedging angles were measured at concave and convex sides of the primary curve apex, and one segment superior and inferior to the apex (functional spinal unit). Disc wedging was measured one segment superior and inferior to the apex.

## Results:

Improved curves: There were 68 patients in the study; 45 (66%) improved by  $9.7^{\circ}\pm4.2^{\circ}$ . From pre-brace to in-brace, vertebral body height changes were greater on the concave vs. convex sides (p<0.001). Vertebral and disc wedging angles were greater pre-brace vs. in-brace (p<0.001). From pre-brace to post-brace, vertebral body height changes were greater at concave vs. convex sides (superior 3.0 mm vs. 2.4, p=0.007; apical 3.2 vs. 2.5, p=0.015; inferior 3.4 vs. 2.7, p=0.011). Post-brace vs. pre-brace, vertebral wedging angles were smaller (superior 1.5° vs. 0.7°, p=0.030; apical 2.1° vs. 0.8°, p=0.004; inferior 2.2° vs. 1.0°, p=0.008) and disc wedging angles were smaller (superior 2.9° vs. 1.0°, inferior 4.3° vs. 1.9°, p<0.001).

Progressive curves: 23 curves progressed by 13.3°±8.1°. From pre-brace to post-brace, vertebral body height changes were greater at convex vs. concave sides (apical 3.5 mm vs. 2.3, p=0.029; inferior 3.6 vs. 2.8, p=0.030) but not superiorly. Post-brace vs. pre-brace, vertebral wedging angles were larger (apical 3.0° vs 4.8°, p=0.033; inferior 3.2° vs. 4.5°, p=0.005) but not superiorly. Disc wedging remained unchanged.

Conclusions: We observed vertebral body growth modulation in patients whose curves improved from brace treatment demonstrated by improved vertebral symmetry, but not in patients whose curves progressed. We hypothesize this may be due to the Hueter-Volkmann principle applied orthotically across the curve apex in skeletally immature patients.

Significance: This is the first study to demonstrate that brace treatment leads to vertebral growth modulation in children with idiopathic scoliosis and thus overall improvement in curve magnitude.

Fig of A) pre-brace, B) in-brace, and C) post-brace radiographic measurements at superior, apical, and inferior segments of primary curve:



## Prosthetic Challenges for a Child with Popliteal Pterygium After Knee Disarticulation

Don Cummings, CP, LP

#### Short Bio of all Presenting Authors

Director of Prosthetics, Scottish Rite for Children

- On staff there for 37 years (since 1987)
- Grew up in Ecuador with parents who were missionaries
- 1981 B.S., General Special Education, UT Dallas
- \* While attending Letourneau University, I acquired bacterial meningitis resulting in bilateral below knee amputions
- 1984 graduate of UT Southwestern's Prosthetic-Orthotic Program
- 1987 Joined hospital as director of prosthetics
- \* Has been actively involved with Hospital's Amputee Ski Trip for 37 years
- \* Has spoken and presented many times and published numerous articles on pediatric prosthetics.

#### Abstract

Popliteal Pterygium Syndrome (PPS) is a rare genetic condition of unknown etiology that causes webbing of the joints, in particular knees ankles and elbows. The subcutaneous fibrous band and webbing can extend from the Ischial Tuberosity to the heel and includes the Popliteal Artery and Sciatic Nerve. Surgical correction can be challenging and ineffective. A 10 year old boy with right PPS, congenital scoliosis, history of tethered cord release, inability to extend either hip past 40 degrees, 60 degree right knee flexion contracture, right cleft foot, 45 degree left knee flexion contracture, crouched gait, acute pain and multiple other issues, was evaluated for possible right knee disarticulation. Preoperatively he was ambulatory and very active using forearm crutches, a left AFO and right equinus prosthesis. But his right knee flexion contracture worsened with increased pain in his right knee and inverted right cleft foot, along with decreasing ability to ambulate. Right knee disarticulation was performed at age 10 + 4. Several challenges required unique prosthetic solutions. The child's inability to extend his hips beyond 40 degrees, along with the existing left knee contracture, meant that he continued to walk with a very crouched gait. The residual limb was bulbous distally with sensitive skin around the femoral condyles. The prosthesis needed to reflect marked knee flexion and ankle dorsiflexion to position the foot beneath the child's center of gravity. A sub-ischial socket with liner and suspension pad was constructed with a single axis locking knee attached in about 30 degrees of flexion. A pediatric hip disarticulation pylon with an angled connector was used to place the multiaxial foot in dorsiflexion. Later a pediatric shock/torque absorber was added. The patient is walking well with this system using forearm crutches.

# Hip-pa-palozza- Complex Hemipelvectomy with Scoliosis

## Edward Krische, MS, CPO, LPO, and Kylie MacDonell, PT, DPT

## Short Bio of all Presenting Authors

Edward is an ABC-certified Prosthetist/Orthotist at Scottish Rite for Children in Dallas, where he specializes in pediatric prosthetics. He holds a Bachelor of Science degree in Biomedical Engineering from Binghamton University-SUNY and a Master of Science in Orthotics and Prosthetics from Baylor College of Medicine. Through Baylor's renowned rotating residency clinical program, Edward gained valuable experience working with a diverse range of prosthetists and orthotists across the United States. Upon graduating, he joined Scott Sabolich Prosthetics and Research, where he refined his clinical and technical skills in a high-volume, high activity patient-centered environment. He later advanced to the role of Clinical Manager at the Dallas facility. Driven by his passion for pediatric prosthetics, Edward became a part of the Scottish Rite prosthetic team in the summer of 2023. He has developed a particular interest in complex amputations (such as hip disarticulations, hemipelvectomies, and rotationplasties), clinical education, and the integration of additive engineering technologies (3D scanning/printing) in prosthetics care. Edward remains committed to advancing the field of pediatric prosthetics, continually striving to improve patient outcomes through innovation, education, and collaborative patient-centered care.

Kylie is a dedicated pediatric physical therapist currently practicing within Richardson Independent School District. She earned her Bachelor of Science in Kinesiology from Temple University in Philadelphia, Pennsylvania, and her Clinical Doctorate of Physical Therapy from the University of St. Augustine in Austin, Texas. After completing her doctorate, Kylie began her career as a pediatric home health therapist before joining Scottish Rite for Children in Dallas, Texas, in 2021. During her time at Scottish Rite, she developed a passion for working with the cerebral palsy population, focusing on neurological injuries and early intervention strategies. She advanced to oversee the intensive rehabilitation program, where she collaborated closely with the Scottish Rite prosthetics team and provided inpatient rehabilitation for complex cases following various orthopedic procedures. Throughout her first five years of practice, Kylie gained diverse experience across multiple settings, including adult inpatient rehabilitation, geriatrics, and pediatric acute care. This year, she transitioned to Richardson ISD to continue her mission of helping children grow and learn in innovative and challenging ways. Kylie remains most passionate about increasing independence and access for her patients, empowering them to reach their full potential at home and in their communities.

## Abstract

## Case Study 1:

17 y.o. male patient presents during clinic for initial evaluation of his left hip disarticulation amputation due to osteosarcoma. It is currently Winter of 2024 and patient was amputated in September 2015. Patient has been ambulating with forearm crutches for almost 10 years with no complaints of overuse or shoulder aggravations. Patient has recently decided that he wants a prosthesis for walking across the stage for graduation and to ambulate around college. His number one activity he hopes to achieve with his prosthesis is to do parkour moves in the future.

The challenging part of this case was initial gait training. Patient had been ambulating for so long now without any prosthetic intervention that his physical therapist and prosthetic team were unsure what his gait patterns would be. Patient underwent a weeklong program of extensive gait training. Videos would be included in the presentation of his time working in PT and coaching tips used to help initiate proper ambulation. Patient does have minor vaulting which is expected for a hip disarticulation patient.

## Case Study 2:

Patient presents in prosthetic clinic for second evaluation for a partial hip disarticulation prosthesis, with her grandparents, who are her primary caregivers. Patient is a 2-year-old female that presents with VACTERL contributing to spina bifida, scoliosis, and transverse deficiency of the right lower extremity. Patient had been working with Scottish

Rite's scoliosis team, recently, to receive a TLSO to help address a 41 degree, left lumbar curve, from T10 to L5. Grandparents report that the patient is pulling to stand and scooting on her left foot when she is standing. Grandparents are hoping to find a solution to help the patient stand and become more mobile without needing assistance. Both the scoliosis team and prosthetic team are worried about decreasing curve progression and suspending the prosthesis properly to allow for maximum ambulation.

Patient's X-ray showed some development of an ilium and upon palpation there were bony landmarks of the posterior ilium and posterior superior iliac spine but no defined structures. Patient had not been compliant about wearing her current TLSO and our fear would be further noncompliance and curve progression. To try and treat both the lower limb loss and scoliotic curve, the prosthetics and orthotics teams tried to use a TLSO-Hip Prosthesis with a reciprocating gait orthosis (RGO) movement plate. For this concept, we casted from nipple line distally. One clinician was trying to get as much spinal correction as possible while the other was addressing getting the best shape around the hemipelvis.

For prosthetic/orthotic design, one clinician focused on applying the correct forces to address the scoliotic curve while the other clinician ensures proper shaping of the residual and gaining enough suspension for the prosthesis. The technicians were key on implementing the RGO portion of the intervention. A thermoplastic thigh section was created, for the prosthetic side, to allow for the reciprocating weighted gait movement of the prosthesis/orthosis. An anterior panel was used to help suspended the prosthesis/orthosis in place while giving the patient a softer interface for the thoracic section. Grandparent were able to don prosthesis/orthosis successfully. Patient was able to use the prosthesis/orthosis with coaching from PT and prosthetists/ orthotists. With an In-brace X-ray, patient curve progression was held at current level. Patient trialed the prosthesis/orthosis for 3 weeks to ensure family felt comfortable with proper use and patient found it successful.

Family found it hard to use for everyday life. Patient has gastrointestinal issue that the anterior panel was causing more pressure to the abdominal area. Family had trouble keeping the prosthesis/orthosis on for long periods of time because of the heat of the prosthesis/orthosis and difficulty for the patient to sit and stand. Ultimately, patient could ambulate with coaching and minimal assistance but the family did not think this would be good for a long term option. Patient was made a traditional hemipelvectomy prosthesis out of thermoplastic to help not bind her gastrointestinal system as much and heat relive areas as need. Patient worked with prosthetics and PT for intensive week of gait training.

## Case Study 3:

Patient is seen for the first time in prosthetic clinic for evaluation of a congenital right hemipelvectomy prosthesis. Patient is only 11 months old and trying to pull to stand. Patient was diagnosed with prenatal caudal regression syndrome and sacral agenesis that led to the absence of a right lower extremity at birth. Patient has full sensation of the contralateral side and has full range of motion and strength. Patient presents as a true hemipelvectomy on the ipsilateral side with a small appendage from the anterior right hemipelvis area. Patient is hitting correct developmental milestones and parents are eager about helping the patient stand and walk.

The two leading concerns for this prosthesis was suspension and having the correct componentry distally to allow for success gait training while still allowing for crawling and sitting. Prosthetics, physical therapy, and the orthopedic team all collaborated on what would be best for the patient. The prosthesis was able to fully suspend with a blended flexible and rigid prosthetic socket interface. The patient could slip out of the prosthesis if she flexed to far forward at the waste. This will be addressed further as patient hits further along in skeletal maturity.

The prosthesis was initially design with a single axis pediatric knee backwards to try and help with sitting while still allowing a higher resistance joint for standing. A hip joint wasn't used due to the weight of the joint and the extreme posterior placement of the prosthetic foot while ambulating. Patient did successfully stand and ambulate but had trouble sitting and having too much of a hip imbalance with the length of the knee. During test fitting and gaiting training, the knee was turned to its proper alignment. Patient was able to stand and crawl easier. Patient could sit with bending her knee and having her prosthetic foot go behind her. Patient worked with physical therapy about moving objects around at quiet standing and taking initial step. Patient does at times have forward progression with her prosthesis but more work with physical therapy and natural progression at home is needed.

# Maintaining Spinal Flexibility in a Patient with Congenital Limb Deficiencies

Lizabeth Bunkell, PT, Jaysson Brooks, MD, and Lane Wimberly, MD

## Short Bio of all Presenting Authors

Liz Bunkell earned her Bachelor of Science Degree in Physical Therapy from California State University, Northridge in 1995 and went on to work in a variety of settings during her first several years out of school. In 2002 she opened her own multidisciplinary therapy clinic, Pediatric Therapy of Santa Clarita, in Southern California. There she served as the Program Director, as well as a treating Physical Therapist. Additionally, she provided free developmental screenings to the community, contracted with the local school districts, provided hippotherapy at a therapeutic riding center, and worked in the level III Neonatal Intensive Care Unit. She received her PT Board Certification as a Pediatric Clinical Specialist in 2008.

In 2021, she sold her practice and moved with her three boys to The Colony, Texas. She started with Scottish Rite Hospital in Dallas, as their PT in the Movement Science Laboratory. She performs clinical gait studies as well as research-focused gait and movement analysis using 3-D motion capture. She enjoys continuing to work with patients as well as being able to grow professionally in her new research role. Her current projects include research within the areas of Hereditary Spastic Paraplegia, Cerebral Palsy, and Scoliosis. She is a member of the Gait and Clinical Movement Analysis Society.

## Abstract

Our patient is a ten-year-old boy born with congenital absence of all extremities: bilateral upper limb phocomelia (short humeral segments) and bilateral lower limb amelia. At the age of four years, our patient demonstrated how he colored by holding a marker against his chin using his right arm. In order to perform this, trunk flexibility and balance is of extreme importance for a patient with his level of involvement. During a follow-up visit, at the age of six years, it was noted that one shoulder was higher than the other. X-rays revealed a thoracolumbar curve of 39°. Our patient met the criteria for brace treatment and was prescribed night time use [1].

After one and a half years of brace wear, at the age of seven and a half, he was seen for follow-up. His parents report decreased adherence to brace use due to growth and believing it was causing increased gastrointestinal issues. His x-rays revealed a curve of 60° at this visit; however, surgical intervention was not considered due to the need for him to maintain spinal flexibility for his independence, so he continued bracing. The patient came in after another six months and the curve had decreased back to 39°. At this time, it became apparent that he was able to "sit up straighter" and reduce the curve, or "slouch" and sink into it. Night time brace wearing continued for several years.

When he returned at age ten, his curve was found to still be at 62° and he was only completing 4-8 hours a day of brace wear, therefore surgical considerations were discussed. Unfortunately, fusions typically result in a significant loss of spinal motion which in turn have negative effects on the independence and quality of life of children with amelia [2]. Anterior vertebral body tethering (AVBT) was discussed as an alternative method for treatment. AVBT involves attaching a flexible cord to the convex side of the curve of the spine, which provides some immediate correction but primarily acts by providing guided growth correction [3]. The family decided this was the best option given the patient's condition.

Due to the rarity of phocomelia/amelia patients, and the lack of data regarding the use of AVBT for treatment of scoliosis in this population, the spine surgeon decided to utilize the movement science lab to look at the spinal flexibility of this patient before and after his tethering procedure. 3-dimensional motion capture was used to collect range of motion with him sitting on the floor. Our patient underwent AVBT of T8-L4 with no complications. On the day of surgery, his thoracolumbar curve measured 66°. One-year post, he had improved and was more balanced on the floor and was no longer reporting being afraid of falling over. His family reported that he was back to moving around the house on the floor. X-rays at that time showed intact instrumentation and good curve correction in the coronal plane, measuring 12°. \*Follow-up with Movement Science is still pending.

# Boosting Independence with Adaptive Equipment for Children with Limb Difference

## Vivian Yip, OTD, OTR/L

## Short Bio of all Presenting Authors

Vivian Yip OTD, MA, OTR/L has worked with children with limb difference for nearly twenty years and is currently an occupational therapist at UCLA Orthopaedic Hospital. She has been a member of ACPOC since 2006 and has presented various topics pertaining to limb difference and prosthetics at ACPOC as well as MEC, AOTA, OTAC, Skills For Life, AOPA and various MOT programs. She has various publications including a co-authored chapter in the Atlas of Amputation and Limb Deficiencies and Pediatric Rehabilitation text book. She has been active with Camp No Limits, Challenged Athletes Foundation, and Angel City Sports.

## Abstract

Children with limb difference may or may not be fitted with a prosthesis or orthosis for different reasons. Whether they are fitted or not, an evaluation by an occupational therapist can assist with boosting independence with adaptive equipment or compensatory strategies. Our population of children are often unique and require customization of adaptive equipment. An overview of adaptive equipment available and how it can be further customized to increase children's independence in daily life activities and tasks through all stages of development will be provided. This will include a review of the new Enhancing Skills for Life Hands Free Catalog.

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# Affected Muscles of Children Born with Upper-Limb Deficiencies Retain Proportional Motor Control

Eden Winslow, BS, Justin Fitzgerald, BS, Michelle James, MD, Wilsaan Joiner, PhD, and Jonathon Schofield, PhD

## Short Bio of all Presenting Authors

Eden Winslow is a 3rd Year Biomedical Engineering PhD student at the University of California - Davis, under the guidance of Dr. Jonathon Schofield. She is performing research on upper-limb prostheses for children born without a hand, investigating the feasibility of proportional control.

## Abstract

**Introduction:** Children with Unilateral Congenital Below-Elbow Deficiencies (born without a hand, UCBED) have a high rate of prosthetic abandonment [1], pointing to unresolved challenges that may be distinct from those faced by adults with limb loss. There is limited knowledge of the motor control these children have over their affected muscles [2], [3], a highly relevant question for dexterous prosthetic control. Our research aimed to measure the extent of volitional, proportional muscle activation that exists in the residuum when children attempt moving their missing hand to varying levels of closure. This information is critical for creating highly functional, pediatric-specific prosthetic devices [4].

**Materials and Methods:** We recruited N=30 pediatric participants (ages 9-19 years, Avg. 13.7 ± 3.1 years, 16 male, 14 female) with UCBED from 4 Shriners Children's Hospital locations (Northern California, Portland, Greenville, Chicago). We employed ultrasound imaging to capture the muscle activity of participants' affected and unaffected limbs while they attempted a cursor control task [5]. Participants used their forearm muscles to move a cursor up and down the screen—attempting to close their hand would move the cursor up, and opening their hand moved the cursor down—and they were instructed to try and match their cursor position with target lines that appeared randomly at 5 levels on the screen. We then analyzed the movement of the recorded cursor activity.

**Results and Discussion:** All N=30 participants showed a significant level of proportional position control in both their affected and unaffected limbs. Their average stable cursor positions, when separated by target level, were all significantly different from one another (p<.0001), as shown in Figure 1, indicating an intentional degree of control and ability to achieve discrete proportional positions. A 2-way ANOVA test revealed there was no significant difference between participants' affected and unaffected limbs (p=.1557), suggesting that the muscles in children's missing limbs are capable of the same complexity of control as their intact hand.

**Conclusions:** The design of effective dexterous prosthetic control systems requires a clear understanding of the motor capabilities of the user. The results from the study indicate that children with UCBED have a robust level of proportional control over their residual muscles, and thus likely possess innate potential to effectively operate advanced prosthetic control systems.





Figure 1: Average stable cursor position, separated by target location (colors), for each of N=30 participants.

# One Size Doesn't Fit All: Choosing the Correct Upper Extremity Prosthesis

Alyssa Barre, MD, Eric Miller, L/CPO, and Janet Walker, MD

## Short Bio of all Presenting Authors

Alyssa is a PGY-3 Orthopaedic Surgery Resident at the University of Kentucky planning to pursue pediatric orthopaedics with a special interest in limb deformity and skeletal dysplasia.

Eric is the Manager of Orthotics and Prosthetics for Shriners Children's Lexington

## Abstract

We present a case of an adolescent girl with a history of congenital left below elbow transverse. deficiency that illustrates challenges of selecting the appropriate upper extremity prosthesis.

During her elementary years, she intermittently wore a passive prothesis, which she found to be hot and uncomfortable. Despite these challenges, adaptive equipment allowed her to play the. ukelele, sparking her interest in active prostheses. At age nine, she received myoelectric prosthesis; however, she felt it to be cumbersome and heavy, causing her soreness. Despite undergoing extensive occupational therapy to improve usability and tolerance, she ultimately stopped wearing the prosthesis for two years.

Upon returning to our clinic, she expressed a desire for a new prosthetic solution that would accommodate her new interests in swimming and art. After discussing multiple options, she chose a voluntary opening below-elbow prosthesis. Since transitioning to this device, she has worn it daily and reports feeling happy and is active in her pursuits.

This case emphasizes that, while myoelectric prostheses represent and exciting frontier in prosthetic technology, individual patient preferences and tolerances play a crucial role in successful prosthetic outcomes.

# Pediatric Knee Disarticulation Gait Deviation Case with Complex Cardiac and Neurological Comorbidities

## Kaitlin Rivest, MSPO, CPO, Rebecca Siegel, MD, and Julia Pines, Prosthetic Resident

## Short Bio of all Presenting Authors

Kaitlin Rivest is a Certified Prosthetist Orthotist at Boston Children's Hospital and the Assistant Resident Director for OPSB/Boston O&P. She is passionate about patient care, utilizing a multidisciplinary approach to foster strong relationships and achieve improved patient outcomes. Valuing lifelong learning, Kaitlin takes pride in mentoring residents and is committed to their education, ensuring ethical practice and upholding clinical standards for superior results.

## Abstract

## Background

Patient is a 3-year-old female with complex medical history including multiple cardiac surgeries, including a Glenn procedure for double inlet left ventricle (DILV). Her hospital course was complicated by left middle cerebral artery (MCA) stroke, resulting in right hemiplegia in addition to right lower extremity ischemia caused by a common femoral artery thrombosis, which required medical and surgical thrombolysis. These severe cardiovascular and neurological issues significantly impacted the patient's rehabilitation process following a right knee disarticulation.

## Case Description

The patient underwent knee disarticulation in September 2021. Initially following amputation, she had a 40-degree hip flexion contracture, making prone positioning painful and limiting therapy to side-lying activities. With physical therapy intervention, the contracture decreased to 5 degrees by February 2022. She continued to have gait deviations including right circumduction and hip hiking. Muscle imbalances due to her stroke and right sided weakness further complicated her gait, she had stronger gluteus medius and tensor fascia lata muscles which overpowered her weaker adductors. These biomechanical challenges required a specialized approach to her prosthetic care and therapy.

Early prosthetic management occurred while the patient was still hospitalized and receiving Milrinone, a medication critical to her cardiac stability. The initial prosthetic fitting involved a single-axis knee with a manual lock to provide basic support and reduce fall risk. This prosthesis was only a temporary solution as the patient began to outgrow it, both physically and functionally.

## Challenges and Prosthetic Solutions

The evolving challenges in this case stemmed from the patient's unique muscular imbalances and the development of a significant abduction contracture. We ordered a polycentric knee joint for her second prosthesis for increased stability and set in standard bench alignment. This however, inadvertently exacerbated her gait issues by encouraging excessive circumduction and further increasing her abduction contracture to 15 degrees. This was especially noted during play, as she found it easier and faster to run without bending her knee. However, she could bend her knee when prompted, showing that with further therapy and prosthetic adjustments, her functional potential could continue to improve.

In the patient's newest prosthesis, during a diagnostic fit, dynamic alignment was assessed with the weight line positioned behind the prosthetic knee joint to intentionally reduce stability, encouraging her to flex the knee during the swing phase. Within minutes, she was able to adapt to this and walked with a completely normal gait pattern.

## Therapy and Progress

Rehabilitation initially required the use of a walker for short distances and a wheelchair for longer distances. Over time, with ongoing physical therapy and adaptation to her prosthesis, the patient became more independent. From the start, she was able to independently don her prosthesis, a notable achievement given her neurological deficits.

Despite the persistence of circumduction, the patient made considerable strides in mobility, balancing the demands of her complex medical background with the need for functional independence.

#### Conclusion

This complex pediatric knee disarticulation case illustrates the challenges of managing prosthetic care in the presence of significant cardiac and neurological comorbidities. It highlights the critical role of individualized prosthetic solutions, ongoing therapy, and multidisciplinary collaboration in achieving the best possible outcomes.

# The Risk of Overgrowth Following Transtibial Amputation is Dependent on Age at Initial Surgery

Anne Marie Dumaine, MD, **Corey Gill, MD/MA,** Claire Shivers, BS, Kelly Jeans, MS, Jessica Laureano Phillips, MS/MPH, and Chan-Hee Jo, PhD

## 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 medical school and orthopaedic residency at Washington University in St. Louis, followed by a Fellowship in Pediatric Orthopaedic Surgery at the Scottish Rite Hospital for Children. 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

<u>Introduction:</u> Terminal limb overgrowth is the most common complication after transtibial amputation in pediatric patients. Overgrowth leads to significant morbidity including pain, inability to wear prostheses, and the need for surgical revisions. A more comprehensive understanding of the epidemiology, risk factors, and surgical techniques associated with overgrowth treatment is needed to better educate families and clinicians involved with care of pediatric amputees.

<u>Methods</u>: We performed a retrospective chart review of transtibial amputations within our Institutional Registry of Lower Limb Deficiency Patients (n=1051). Patients were included if they had transtibial amputation for any reason, were <18 years of age, and had >1 year of follow up.

<u>Results:</u> 191 patients with 213 transtibial amputations were included in the study. Mean age at amputation was 6.34 years (0-17.96) with a mean follow-up of 9.7 years (1.1-20.1). Over half of patients (108/191) required amputation revision for symptomatic overgrowth with a median of 2.00 revisions/limb (range 1-10). The highest incidence of overgrowth was in patients with amniotic band syndrome at 73.7% (28/38). Mean age at initial amputation was lower in patients developing overgrowth (4.51 years) compared to those with no overgrowth (8.58 years) (p<0.0001). The incidence of overgrowth was 2.2-fold higher in patients with initial amputation < 10 years of age (66.2%, 96/145) compared to patients >10 (30.3%, 20/66). There was moderate negative correlation between age at initial overgrowth revision surgery and total number of revisions (r= -.57, p<0.0001). At the time of initial overgrowth revision, 93 limbs underwent simple resection versus 24 limbs with modification performed (osseocartilaginous capping, modified Ertl, osseous canal plugging) to prevent future overgrowth. While modifications trended towards a longer time between subsequent revisions (3.10 years vs 2.26 years, p= .1093), the need for a subsequent revision was not changed.

<u>Conclusions</u>: Most pediatric patients with transtibial amputations develop overgrowth (56.5%). Younger age at initial amputation is associated with increased risk of overgrowth and the need for multiple revision amputations. Treatment for overgrowth is the rule rather than the exception for diagnoses leading to transtibial amputation at a young age such as amniotic band syndrome. Future studies are needed to identify effective interventions for preventing overgrowth in this population.

<u>Significance</u>: Within the literature, this review consists of the largest cohort of transtibial pediatric amputee patients with the highest documented incidence of overgrowth and provides important information for counseling patients on risk of developing overgrowth based on age and etiology of amputation.

# Table 1: Incidence of overgrowth by age in pediatric transtibial amputees

Age at amputation	Total (number	No overgrowth	Overgrowth	
(years)	of patients)	(percent%)	(percent%)	
Less than 5	109	36 (33.0)	73 (67.0)	p < 0.0001
5-10	36	13 (36.1)	23 (63.9)	
10-15	45	27 (60.0)	18 (40.0)	
Greater than 15	21	19 (90.5)	2 (9.5)	

# 3.4 Million Living with Limb Difference – US Prevalence Data and the Implications for Public Policy

## Ashlie White, MSHLS, MA

## Short Bio of all Presenting Authors

Ashlie White is the Chief Strategy and Programs Officer at the <u>Amputee Coalition</u> and serves as the Principal Investigator (PI) for the Administration for Community Living (ACL) National Limb Loss Resource Center (NLLRC). Prior to joining the Coalition, she served as the Director of Health Policy and Strategic Alliances for the American Orthotic and Prosthetic Association (AOPA). She began her career in health advocacy work on the operations side of her family-owned prosthetics and orthotics patient-care practice. During her time as Director of Operations at Beacon P&O, she also served eight years as Director of Government Affairs for the North Carolina Orthotics and Prosthetics Trade Association (NCOPTA) and four years on the board of Directors for the National Association for the Advancement of Orthotics and Prosthetics (NAAOP). Ms. White recently completed NYU Law's MS in Health Law and Strategy graduate program and holds a graduate certificate in Public Health Leadership from UNC's Gillings School of Global Public Health. She also holds MA and BA degrees from the School of Journalism at the University of North Carolina at Chapel Hill. She currently splits her time between Washington DC and Durham, North Carolina.

## Abstract

The Amputee Coalition's newly commissioned study titled, Prevalence of Limb Loss and Limb Difference in the United States: Implications for Public Policy, published by Avalere Health, shows that there are 5.6 million individuals living with limb loss or limb difference in the United States, 3.4 million living with limb difference. This presentation will provide an overview of this first-of-its-kind study and the public policy implications of its results, specifically focusing on data related to the prevalence of limb difference and pediatric amputations.

## Learning Objectives:

- Upon completion, participants will be able to describe the recently published prevalence data for the limb loss and limb difference population.
- Upon completion, participants will understand the limitations of the retrospective claims review data, including populations not captured in the data set.
- Upon completion, participants will be able to discuss trends in the data specific to the most prevalent limb difference diagnoses and the most common diagnoses preceding amputation for the pediatric population.

# Do PODCI and Gait Scores Change Overtime in Children with Lower Extremity Limb Deficiency? Is there a relationship between PODCI and Gait Scores?

Kelly Jeans, MS

## 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

The Pediatric Outcomes Data Collection Instrument (PODCI) has been used as a patient reported outcome tool in children with upper1 and lower extremity limb deficiency.2-5 Significant factors affecting this patient group include underlying diagnosis (congenital v acquired), deficiency level, age, laterality, etc. While previous studies have shown Adolescents score themselves higher functioning than their parents perceive3,4, it is unknown if there is a relationship between perceived function and objective measures of function, including gait and walking speed. A recent report looking at change in gait compensation patterns, showed little change over time6, however, it is unknown if patient reported outcome scores reflect this result.

## Methods

As part of an IRB approved study, children with lower extremity limb deficiency were invited to undergo 3D gait analysis and PODCI testing at 2 time points. The Gait Deviation Index (GDI) was calculated for the involved limb(s)7 using 100 control subjects as reference data. Walking speed (% of TD) was also included. The parent/adult PODCI along with the adolescent report from Visit2 included the four subscales (UpperExtremity, Transfer/Basic Mobility, Sport/Physical Function and Pain/Comfort), Happiness and the cumulative Global Function score. Statistical analysis was conducted with alpha set to 0.05.

## Results

A comparison of PODCI results between Visit1 (age 7.3yrs) and Visit2 (15.0yrs; 7.3yrs follow-up) from 42 children (27 F) with limb deficiency (10 Syme, 12 transtibial, 4 knee disarticulation, 2 transfemoral, 9 PFFD and 5 bilateral (4 BK, 1 KD); 34 Congenital & 8 Acquired) can be found in Table 1. Thirty-three participants were also seen for gait analysis. PODCI scores show a significant increase in UpperExtremity, Sport/PhysicalFx and Global Function scores ( $p \le 0.025$ ) at Visit2, while Happiness ratings went down (p=0.021). There were no significant differences in PODCI scores between the parent and the adolescent self-report at Visit2. The GDI improved (p=0.030), but the increase in walking speed at Visit2 (98% v 93%) was not significant (p=0.058). Correlations between adolescent PODCI scores and the GDI and walking speed, showed weak to moderate correlation across all subscales ( $p \le 0.043$ ), except UpperExtremity (p=0.091).(Table 2) There were no significant findings based on congenital verses acquired (p>0.05), however, length of follow-up between visits, was positively correlated with Sport/PhysicalFx (r=0.36; p=0.036), Happiness (r=0.47; p=0.006) and Global function (r=0.40; p=0.019).

#### Discussion

Current results suggest an improved perception of function by the parent between Visit1 and Visit2 with a relatively marginal change in the overall gait score (1.5 change). Correlations across most PODCI scores and GDI and Walking Speed, were seen in the Adolescent self-reports at Visit2, indicating the adolescent report is more indicative of their Gait score and walking speed. These relationships were not made in the parent report at Visit2. It should be noted, that with few exceptions, the PODCI scores were slightly below normative values8 reported by TD children. One exception was with the Happiness subscale. Although it decreased between Visit1 and Visit2, both were WNL. This study highlights the necessity of having adolescents self-report, as they are more closely aligned with functional outcomes.

Table 1		Vis	it1	Vis		
Variable	Ν	Mean	SD	Mean	SD	Р
Age at Visit (years)	42	7.3	2.3	15.0	2.5	
UpperExtremity	42	93.74	7.65	97.82	5.38	<0.001
Transfer/BasicMobility	42	94.09	8.72	96.28	7.66	0.090
Sport/PhysicalFunction	42	74.89	16.93	80.66	17.03	0.025
Pain/Comfort	42	84.40	18.29	85.30	17.33	0.767
Happiness	42	89.61	14.66	83.45	16.40	0.021
GlobalFunction	42	86.78	9.50	90.02	8.54	0.019
GDI Gait Score	33	84.05	4.73	85.56	5.72	0.030
Walking Speed% TD	33	93%	16%	98%	11%	0.058

Non-parametric Wilcoxon's signed rank test

Table 2	GDI			Walking Speed % TD		
Variable	N	Corr	Р	Corr	Р	
Visit2 Adolescent						
TransferBasic Mobility	27	0.39	0.043	0.42	0.031	
SportPhysicalFunction	27	0.51	0.007	0.29	0.142	
PainComfort	27	-0.09	0.649	0.43	0.026	
Happiness	27	0.50	0.008	0.09	0.668	
GlobalFunction	27	0.30	0.128	0.47	0.014	
GlobalFunction	27	0.30	0.128	0.47	0.0	

Spearman correlation

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# War-Related Right Lower Extremity Injury in an 8-year-old Male from Gaza

## Corey Gill, MD, MA

## 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 medical school and orthopaedic residency at Washington University in St. Louis, followed by a Fellowship in Pediatric Orthopaedic Surgery at the Scottish Rite Hospital for Children. 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

## The Problem:

Prior to October 7th, 2023, access to pediatric orthopedic and prosthetic care in Gaza was severely limited, despite sustained efforts of several ACPOC members, NGOs, and local partners. Since the War in Gaza began in 2023, pediatric orthopedic and prosthetic infrastructure has been eliminated, despite estimates of over 1000 new pediatric amputees in Gaza secondary to war-related injuries.

As one example, the patient presented is an 8-year-old male from Gaza City who sustained an open femur fracture secondary to a bomb striking his home on December 4, 2023. He was brought to a hospital in Gaza and noted to have a dysvascular limb. Secondary to hospital resources being overwhelmed, he did not have surgery until 4 days after admission. Initial treatment included I&D and external fixator placement. He developed a gangrenous foot and ultimately underwent right transtibial amputation with skin grafting from the ipsilateral thigh to cover the end of the residual limb.

Patient eventually was transferred to Egypt and the external fixator was removed May 4, 2024. At that point, there was a femur nonunion/malunion with shortening and varus deformity of the right thigh, and there was evidence of chronic osteomyelitis on radiographs. There was a 45-degree knee flexion contracture and patient did not tolerate contact over the end of the residual limb. He had not been measured for or worn a prosthesis.

## The Solution:

This patient was brought to the United States for definitive management of his complex injury, with the assistance of an NGO focused on treating injured children from Gaza. The presentation will outline the multidisciplinary approach to his care, including involvement by orthopedic and plastic surgeons, prothetists, psychologists, nurses, child life and therapeutic recreation specialists, and physical therapists.

# Global Challenges in Pediatric Prosthetics and Orthotics Care: A Qualitative Exploration of Professional Perspectives

Shanee Abouzaglo, MD, and Corey Gill, MD, MA

## Short Bio of all Presenting Authors

**Shanee Abouzaglo, MD** is a first-year resident physician at Scripps Mercy Hospital in San Diego, where she is completing her intern year in internal medicine. She will continue her specialty training in Physical Medicine and Rehabilitation at Spaulding Rehabilitation Hospital in Boston. With a particular interest in international physiatry and pediatric rehabilitation, she looks forward to integrating these passions into her training and career.

## Abstract

## Background:

Pediatric limb differences (LD) present significant challenges worldwide, especially in lower- and middle-income countries (LMICs). The World Health Organization (WHO) estimates that 94% of children with LD are born in LMICs, where factors leading to pediatric amputation disproportionately fall and where access to orthopedic treatment or prosthetics and orthotics (P&O) care is often limited. Despite technological advances and organizational efforts, access to quality P&O services remains a global challenge. This study explores perspectives of professionals providing pediatric P&O care in various global contexts, aiming to understand care challenges and identify potential solutions. It was hypothesized that while challenges in the amputation care continuum might mirror those encountered by adults, there would be distinct features to pediatric care that exacerbate difficulties in accessibility and affordability of quality P&O care on a global scale.

## Methods:

Semi-structured virtual interviews were conducted with 12 P&O professionals who had international work experience. Interviews were about 45-minutes in duration and interviews were transcribed in a clear verbatim approach. Through an iterative deductive-inductive approach, thematic analysis was performed to meaningfully represent the discussions on barriers and facilitators in global pediatric P&O care.

## **Results:**

P&O professionals with experiences in 16 countries across 5 continents described a complex landscape, and 6 key themes emerged:

- 1. **Limitations of Personnel and Products:** A shortage of skilled professionals, maintaining a trained workforce, and inconsistent availability of appropriate materials and technologies led to variable quality of care.
- 2. Barriers to Accessing Services: Geographic challenges, especially for patients and families living in rural areas, were often compounded by financial constraints and sociocultural factors which impacted access to care.
- 3. Working within Systems: Collaboration with existing healthcare systems, medical communities, and local and national government support varied across regions, influencing care delivery.
- 4. **Continual Childhood Needs:** Pediatric patients required pediatric-specific components and ongoing adjustments due to their development, which exacerbated the strain on resources and services.
- 5. **Supporting Families and Patients:** Family involvement was critical in the rehabilitation of children with P&O needs; however, many families faced overwhelming social and financial pressures.
- 6. Holistic and Person-Centered Care: A comprehensive, child-first approach focusing on community integration, education, and long-term rehabilitation was emphasized as crucial for successful outcomes.

## Conclusions:

The interviews highlighted intricate global challenges in P&O care that are particularly nuanced in children. The study calls for systematic improvements in policy, workforce development, and material sourcing to create sustainable, quality pediatric P&O care. Moreover, a child-first approach, which addresses growth-related prostheses adjustments, family support, and community integration, is paramount to improving quality of life for children with LD.

#### Significance:

Children with LD have unique and evolving prosthetic and orthotic needs as they grow, necessitating multidimensional approaches to optimize care. For children in resource-limited environments, strategies must be child-centered and context-specific to effectively meet the needs of these vulnerable populations. Global health initiatives should focus on developing accessible, appropriate, and sustainable P&O care to meet the needs of children with LD worldwide.

# Understanding the Impact of War and Trauma on Children. Is there an emerging Global Health Crisis?

Zaria Shah, Colleen P Coulter PT, DPT, PhD, Tom Adamkiewicz MD, FRCP, MSCR, FAP, Corey Gill MD, MS

## 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.

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 immediate past 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

According to this year's United Nations (UN) Report on Children and Armed Conflict the number of children killed (5301) and maimed (6348) increased overall in 2023 by a staggering 35% as compared with 2022.1 Civilians represented 63% of casualties from explosive weapons in 2021 and 2022.2 Often over 40% of civilian casualties are children. Global Burden of Disease database prevalence of unilateral lower limb amputation among children up to the age 14 years old was estimated to be 92,496 from conflict and terrorism in 2017, the third leading cause globaly.3 In a systematic review of trauma and rehabilitation interventions to women and children in conflict settings, out of the 81 studies reviewed, the most reported interventions were orthopedic reconstructive surgery and amputations.4 Barriers identified included capacity to manage and stabilize trauma cases at site of injury, transportation, safety, expertise for management of trauma cases, collaboration, appropriate medical supplies and surgical equipment, paucity of data on follow up if this occurred at all. Additional possible gaps related to limb injury care include prevention strategies (conflict prevention and civilian harm reduction during military operations), physiological needs of children (optimal tourniquet use, shock, hypothermia, transfusion, optimal limb salvage technics, healing, rehabilitation, orthotics, growth, holistic support); cost; understanding practical and ethical challenges of working and collecting data in austere environments.

Capturing the data on numbers of children who are critically injured in areas of war and conflict is limited if not absent. Children are innocent victims sustaining unimaginable injuries if not death in areas of conflicts such as Ukraine, Israel and Palestinian Territories including Gaza, Lebanon and other conflicts. Medical, surgical, rehabilitation, and prosthetic/orthotic interventions are not adequately documented. Therefore, information reporting short- and long-term outcomes are absent in the literature.

## Solution-

Perform a systematic review of the literature on Pediatric limb injuries in armed conflicts and the global impact of war and trauma using PRISMA focusing on:

• Estimate epidemiology

Population incidence and prevalence

Rates per case series

• Report (with available data)

Mechanism of injuries

Types of injuries

Location of care

- Describe immediate and long-term care, what works, and gaps
- Estimate lifelong costs
- Form a multidisciplinary team to identify the need for awareness of the impact of war and trauma in global areas of conflict on children. The team can include ACPOC members and others with experience in humanitarian service.
- Create a network for communication and to share information

#### Outcome-

- Publish the systematic review in a journal with the focus on pediatric health and wellness and the impact of conflicts and trauma.
- Present at pediatric and orthopedic pediatric association meetings
- Collaborate with others nationally and internationally who have published on this topic
- Identify national and international resources to increase awareness and so others can become involved

# Experiences Delivering Prosthetic, Orthotic, and Rehabilitation Care to Unfunded or Low-Resource Patients

## Gabrielle Nguyen, MD, Sharon Malek, DPT, Brittany Guidry, DPT, and Marina Ma, MD

## Short Bio of all Presenting Authors

Dr. Nguyen completed a Fellowship in Physical Medicine and Rehabilitation at Baylor College of Medicine in 2018, following a Residency at the University of Texas Health Science Center - San Antonio in 2016, and earning her Doctor of Medicine degree from The University of Oklahoma in 2012. She is a member of the American Academy of Physical Medicine and Rehabilitation and serve on the Special Interest Group Committee for the American Association of Neuromuscular & Electrodiagnostic Medicine. Dr. Nguyen believes in a multi-disciplinary, collaborative approach to patient care, valuing input from all members of the treatment team, especially the patient and family, with the aim of helping them achieve their maximum functional potential and personal goals.

Dr. Marina Ma holds a distinguished position as one of the very few physicians in the United States who holds quadruple board certifications in Physical Medicine and Rehabilitation, Pediatric Rehabilitation Medicine, Brain Injury Medicine, and Hospice and Palliative Medicine. She plays an integral role in multidisciplinary clinics specializing in neuro-oncology, spina bifida, and neuromuscular diseases. Working alongside a diverse team of specialists, Dr. Ma collaborates closely to provide tailored and comprehensive care addressing the unique needs of patients with these conditions. Her commitment to enhancing patients' quality of life is demonstrated through her dedication to delivering evidence-based, high-quality care. Dr. Ma's compassionate approach ensures that both patients and their families receive comprehensive and holistic support throughout their care journey.

Sharon Malek is a licensed PT and DPT, also certified in Schroth physical therapy. She is a physical therapist in the TCH Limb difference clinic.

Brittany Guidry is a licensed PT and DPT, certified in Schroth physical therapy. She is a physical therapist in the TCH Limb difference clinic and assist with coordination.

## Abstract

Access to high-quality prosthetic, orthotic, and rehabilitation (P&O) care remains a challenge for patients with limited financial resources, particularly in areas where there is a large population of foreign-born people who do not possess a valid visa or other immigration documentation.

This presentation will discuss our practices for providing comprehensive P&O services to unfunded patients, describing our approaches to mitigate financial barriers while maintaining care standards. Key strategies include identifying non-profit partnerships, developing relationships with different departments and organizations, and utilizing creative solutions for rehabilitation and prosthetics and orthotics. In addition, we will discuss community-based programs, telehealth services, and consider other ways to enhance accessibility and patient outreach.

Long term we hope that government-funded initiatives and advocacy for expanded healthcare coverage can be created as crucial components of a sustainable care model. By discussing and brainstorming these approaches, our hope is that rehab professionals can ensure that all patients, regardless of financial standing, receive the critical support they need to regain mobility and improve quality of life.

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# Effect of Talocalcaneal Coalitions on Foot and Ankle Kinematics in Adolescents

Victoria Blackwood, MS, Kelly Jeans, MS, Rusty Hartman, MS, Jacob Zide, MD, and Anthony Riccio, MD

## Short Bio of all Presenting Authors

Victoria Blackwood was born and raised in North Carolina where she earned her Bachelor of Science degree in Engineering with a concentration in Biomedical Engineering at East Carolina University in 2020. While at East Carolina University she had the opportunity to participate in a summer research internship funded by the National Science Foundation. During the summer she was able to conduct a research project looking at the effects of ACL reconstruction on walking and running biomechanics using Opensim modeling. This opportunity sparked her interest in research which led her to pursue a higher degree. She moved to Lawrence, Kansas and earned her Masters of Science degree in Bioengineering with a concentration in Biomechanics. Her thesis involved looking at postural stability in older adults diagnosed with multiple sclerosis, allowing her to gain insight into clinical research. After graduating in 2022 she moved to Dallas, Texas to begin working as a Biomechanist at Scottish Rite for Children in the Movement Science Lab. Currently at Scottish Rite she works closely with the Foot and Ankle Team completing research projects involving various diagnoses of the foot in adolescent patients. Her research involves studying foot and ankle biomechanics using motion analysis and pedobarography.

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.

Rusty Hartman earned his Bachelor of Science degree from the University of North Texas in Biochemistry and his Master of Science degree from the University of North Texas Health Science Center in Biomedical Sciences with an emphasis in Integrative Physiology. After finishing his master's Thesis, "The Impact of Early Life Stressors on the Progression of SLE", he joined Scottish Rite for Children in 2021, to continue his passion for research. He currently works as the lead research coordinator at the Foot and Ankle Center of Excellence on campus. His research has focused on improving treatment outcomes in clinical populations inclusive to clubfoot, CMT, and other complex foot and ankle deformities.

## Abstract

## Introduction

Talocalcaneal coalitions are one of the most common tarsal coalitions diagnosed in adolescent patients1-3. It occurs when an abnormal connection, either osseous or fibrous, forms between the talus and calcaneus, limiting subtalar motion1-3. The coalition can continue to ossify as patients reach skeletal maturity which causes various symptoms prompting them to seek clinical care3. These coalitions can cause rigid flatfeet, pain, lead to ankle sprains, and other factors affecting daily living1-3. Aside from clinical examination, gait analysis is useful in providing information about how segments move in relation to one another during gait. Multi-segment foot models have been on the rise to accurately analyze segments of the foot since most general models assume the foot to be a single rigid body. It is known that talocalcaneal coalitions limit or reduce subtalar motion, but it is important to understand how it may also impact various segments of the foot during gait.

## Clinical Significance

Reduction of subtalar motion mostly affects function of the hindfoot during gait, but further analysis is needed to understand resulting compensatory patterns that hinder function. Analysis of foot kinematics during initial presentation can set the foundation to determine what aspects may warrant conservative or surgical treatment.

## <u>Methods</u>

The study consisted of a retrospective review of patients from an IRB approved foot and ankle registry. Eleven participants (17 feet) had a confirmed talocalcaneal coalition diagnosis. Fifteen controls (26 feet) were used as the comparative control cohort. All participants underwent gait analysis using a Vicon Motion Capture System. A modified Helen Hayes marker set was used in addition to our SRC foot model to analyze different foot segments relative to one another during gait. The SRC foot model allows motion analysis of the hindfoot segment relative to the tibia, and the forefoot segment relative to the hindfoot. A representative trial was chosen from a set of consistencies for analysis. Statistical analysis was completed by using a non-parametric Mann Whitney U test with p<0.05.

## <u>Results</u>

Table 1 shows the results for the kinematic variables involving the ankle, hindfoot relative to the tibia, and the forefoot relative to the hindfoot.

## <u>Discussion</u>

General ankle motion shows that feet with talocalcaneal coalitions exhibit reduced sagittal plane motion and a more external foot progression angle. Hindfoot motion relative to the tibia shows that the hindfoot in the coalition group remains slightly dorsiflexed during push-off in 3rd rocker. The coalition group also remains in hindfoot valgus during stance with reduced range of motion in the coronal plane. There were significant differences in all kinematic variables amongst all planes of motion when looking at the forefoot relative to the hindfoot. Most notably there is increased plantarflexion seen throughout all three rockers of gait, increased inversion, and increased forefoot abduction. These can be considered compensatory motions to maintain a functional foot while the hindfoot motion is limited.

# Casting and Bracing Tolerance in Idiopathic Toe Walking Individuals with Sensory Processing Differences

Fabiola Reyes, MD, Amy Sitabkhan, OTR, MOT, Linsley Smith, RN, Jennifer Royo, PA-C, and Karina Zapata, PT, DPT, PhD

## Short Bio of all Presenting Authors

Fabiola I. Reyes, M.D., is a pediatric physical medicine & rehabilitation physician in the Neurology and Rehabilitation Medicine Division. She treats the motor control patient population. Her clinical interests include visual gait analysis, instrumented gait analysis, goal directed tone management, and multidisciplinary therapies to maximize function and participation in children affected with cerebral palsy and other physical disabilities. Dr. Reyes tries to set clinical goals for her patients based on the WHO's international classification of function.

## Abstract

<u>Introduction</u>: Idiopathic toe walking is a common variant of gait and natural history suggests most cases resolve by age 10. At our institution, we consider treatment for idiopathic toe walking when it causes pain, interferes with activities, or leads to contractures. An algorithm is used with the eventual goal of initiating an intensive brace protocol followed by a 3-month taper. The ankle-shaft angle is set to neutral dorsiflexion, and if the child has a contracture, serial casting is implemented to allow for dorsiflexion to 10 degrees past neutral.

This study aims to determine if casting and brace tolerance differs in children with sensory processing differences as per Short Sensory Profile (SSP) scores. We hypothesized that children who scored outside the norm on the SSP would have more skin and cast complications and less brace tolerance.

**Methods:** A retrospective chart review was conducted of children seen in a toe walking clinic who had filled out an SSP. Children who had a neuromotor diagnoses, structural findings on neuroimaging, under 3 years of age, and those who were lost to follow up before intervention was conducted were excluded. Data collected from 102 patients and included demographic characteristics, range of motion at the ankle before and after intervention, percentage of time spent on toes before intervention, number of casts placed, and whether cast complications, pain, and brace intolerance occurred. A chi-square test was used to compare categorical variables and for the small sample size Fisher's exact text was utilized. Continuous variables were first examined for normality of data distribution and then a nonparametric test such as Mann-Whitney was executed. Significance was set at p < 0.05.

**<u>Results:</u>** There were no differences in age, gender, or ethnicity between the different SSP cohorts. Those who scored above the norm in both the sensory and behavioral categories of the SSP were more likely to have a neurodevelopmental diagnosis compared to those that scored within the norm (P values of .0013 and .00000 respectively). There were no differences between SSP cohorts with regards to the percentage of time spent on toes, the number of casts placed to reach ankle dorsiflexion goal, or the degree of ankle dorsiflexion achieved after casting. Ankle dorsiflexion before casting was also all the same bilaterally except for those that scored below the sensory norms. There were no differences in number of cast complications or skin problems between the cohorts. Bracing was more likely to be tolerated in the cohort that scored above the norm than those that scored in the norm in sensory category (P value of 0.0250), otherwise there was no difference in brace tolerance.

<u>Conclusions</u>: We rejected our hypothesis. Casting and bracing are tolerated in children with idiopathic toe walking, even in those with concerns for sensory processing differences. Non-surgical treatment should be considered in all children who would benefit from treatment for idiopathic toe walking even when associated with a neurodevelopmental diagnosis.

Table 1: Baseline Characteristics and Casting and Bracing Tolerance Variables

\* Designates a statistically significant difference in values

	Total (N)	Percent Avg Spent on Toes	Avg ADF Before Tx- Right (Degrees)	Avg ADF Before Tx- Left (Degrees)	Avg Weeks in Cast (N)	% Avg Cast Complication	% Avg Skin Complication	% Avg That Tolerated Brace
Normal Sensory Score	63	83	-6.02	-6.67	5.02	10.81	27.03	80.85
Sensory score	33	91	-4.39	-5.1	4.28	15.79	31.58	56.00
above norm		(.3284)	(.5916)	(.5078)	(.3248)	(.6876)	(.6786)	(.0250*)
Sensory score	6	83	1.67	1.67	4.0	66.67	33.33	80.00
below Norm		(.8222)	(.0659)	(.0475*)	(.5233)	(.0536)	(>.9999)	(>.9999)
Normal Behavioral Score	61	85	-5.03	-5.82	5.22	8.57	22.86	77.27
Behavior score	30	89	-5.57	-6.17	3.90	22.22	33.33	57.14
above Norm		(.5813)	(.6187)	(.6332)	(.0860)	(.2110)	(.4126)	(.3817)
Behavior Below	11	82	-3.64	-3.64	4.33	33.33	50.00	66.67
norm		(.7471)	(.6445)	(.5140)	(0.4556)	(.1476)	(.3162)	(.3435)

# A Creative Solution for Toe Walking: Comparing Biomechanical Outcomes Pre vs Post Turtle Brace Treatment

Julie Basset, PT, MSc, **Camille Costa, MD, MSc**, Marianne Gagnon, KIN, MSc, Katerina Jirasek, PT, MSc, Jean-Francois Girouard, ENG, Marlène Beaulieu, MD, PhD, Reggie Charles Hamdy, MD, Louis-Nicolas Veilleux, KIN, PhD

#### Short Bio of all Presenting Authors

Dr. Camille Costa first obtained a degree in physiotherapy from McGill University. She then completed her medical degree at McGill University. Passionate about rehabilitation, she went on to complete her residency in Physical Medicine and Rehabilitation (Physiatry) at the University of Montreal, followed by a subspecialty in Pediatric Physiatry at CHU Sainte-Justine. She also completed a master's degree in Biomedical Sciences at the University of Montreal. She currently works at Shriners Hospital for Children – Canada, Sainte-Justine Hospital, and their affiliated rehabilitation centers, where she sees children with neuromusculoskeletal issues.

#### Abstract

#### Introduction to clinical case

Idiopathic Toe Walking (ITW) is a diagnosis of exclusion [1] that refers to an individual without apparent cause for persistent toe walking beyond two years of age [2], but is able in the first years of toe walking to voluntarily heel-toe gait. Effects of persistent toe walking can result in decreased ankle dorsiflexion range of motion (ROM) [3] and lower extremity musculoskeletal pain. In youths with ITW, the principal non-invasive treatments to reduce toe-walking are physical therapy exercises [4], ankle foot orthosis [5] and serial castings [6]. The TurtleBrace® (thermoplastic brace) is a non-invasive alternative treatment to serial casting which is less time consuming to manage, easier to tolerate, can be remolded and worn in shoes. There is currently a gap in the literature on the efficiency of TurtleBraces® to treat ITW and its effects on the biomechanics of gait. This case study aims to identify objective biomechanical outcome differences between pre-and post-treatment of ITW with TurtleBraces to better determine its effectiveness in normalizing ankle ROM.

## Methods

Four patients, 2 females (6 and 7 years old) and 2 males (5 and 11 years old), diagnosed with ITW were evaluated preand post-TurtleBraces<sup>®</sup> treatment bilaterally 23 hours per day for 6 weeks, at a pediatric

orthopedic hospital in a motion analysis center. Three groups were created for comparison: 1- ITW pre-TurtleBraces<sup>®</sup>; 2-ITW post-TurtleBraces<sup>®</sup> treatment; 3- Database of healthy controls. The participant walked barefoot over ground at a self-selected speed. Retroreflective markers were used to identify specific bony landmarks on the patient. A motion capture system was used to collect kinematic data. For the main outcome measures, ankle joint angles in the sagittal plane were processed, averaged and output for three complete Gait Cycles (GC) on each side. To identify statistical difference, the main outcome measures were compared using statistical parametric mapping between groups 1 vs 2, 1 vs 3 and 2 vs 3.

#### Results

Data showed statistically significant normalization of ankle ROM post-TurtleBraces<sup>®</sup> treatment compared to pretreatment during initial contact through mid-loading response (0.0-5.0% of GC), mid-stance (15.1-26.3% of GC), preswing through early swing (52.7-67.4% of GC) and end of mid-swing through late swing (82.6-100.0% of GC) (Figure 1). Data also showed incursion into ankle dorsiflexion post-TurtleBraces<sup>®</sup> compared to pre-treatment with significant differences on initial contact through mid-stance (0.0-30.1% of GC) and through swing phase (64.4-100% of GC).

#### Conclusion and clinical relevance

The data of the current case study suggest that TurtleBraces<sup>®</sup> normalize ankle ROM in the sagittal plane for approximately 48% of the GC. Although preliminary, the current data set shows the potential of TurtleBraces<sup>®</sup> to improve ankle kinematics in youth with ITW. Larger studies comparing TurtleBraces<sup>®</sup> to serial casting are warranted to conclude firmly on the topic.



Fig 1. Pre-and Post-TurtleBrace Treatment Ankle Kinematics

# Have you Heard of Cerebral Palsy? – Approach and Considerations to Diagnosing, Disclosing, and Discussing Treatment Options in CP

Fabiola Reyes, MD, Angela Shierk, PhD, OTR, Rajashree Srinivasan, MD, and Kelsey Thompson, CPO, LPO

## Short Bio of all Presenting Authors

Fabiola I. Reyes, M.D., is a pediatric physical medicine & rehabilitation physician in the Neurology and Rehabilitation Medicine Division. She treats our motor control patient population. Her clinical interests include visual gait analysis, instrumented gait analysis, goal directed tone management, and multidisciplinary therapies to maximize function and participation in children affected with cerebral palsy and other physical disabilities. Dr. Reyes sets clinical goals for her patients based on the WHO's international classification of function.

Angela Shierk, Ph.D., O.T.R., is a senior clinical scientist at Scottish Rite for Children and an assistant professor at the University of Texas Southwestern in the School of Health Professions. She graduated with a masters in occupational therapy from Texas Tech University Health Sciences Center, and a Ph.D. in occupational therapy from Texas Woman's University. She has worked as an occupational therapist in pediatric settings including outpatient clinics, inpatient rehabilitation, home health, and public schools. Her research focuses on improving upper limb function using a variety of modalities for children with cerebral palsy. Specifically, the research explores the effectiveness of constraint-induced movement therapy (CIMT) with and without the use of virtual reality, therapy following botulinum toxin injections, and the effectiveness of home programs. She also has an interest in patient-centered outcomes research and the engagement of multiple stakeholders in the research process.

Rajashree Srinivasan, M.D., is associate medical director and chief of service – physical medicine and rehabilitation at Children's Health<sup>™</sup>. She specializes in brain and spinal cord injury. I enjoy being a physician who cares for children with special needs, as it's very rewarding. Dr. Srinivasan earned her medical degree from Bangalore Medical College in Bengaluru, Karnataka in India. She then completed her residency training in physical medicine and rehabilitation at the University of Toledo Health Science Campus in Toledo, Ohio. Dr. Srinivasan's research and clinical interests include spinal cord injury and cerebral palsy outcomes.

Kelsey Thompson C.P.O., L.P.O., is a certified prosthetist orthotist at the Scottish Rite for Children Orthopedic and Sports Medicine Center in Frisco. She studied biomechanical engineering at Texas A&M and trained in prosthetics and orthotics at UT Southwestern in Dallas where she also completed a residency in prosthetics and orthotics.

## Abstract

## Goals and Objectives

After the seminar, audience members will:

- 1. Understand the importance of diagnosing cerebral palsy at an early age
- 2. Be familiar with different approaches to diagnosing of infants and older children with CP
- 3. Understand how to use a standardized approach to disclosing a new diagnosis of CP
- 4. Feel comfortable discussing orthotic recommendations after a new diagnosis of CP
- 5. Recognize the importance of early diagnosis within the context of neuroplasticity

**Introduction**: Cerebral palsy (CP) describes a group of permanent disorders of movement and posture attributed to a non-progressive disturbance in the developing brain. It is the most common cause of physical disability in children. The average age of diagnosis in the United States is at about two years of age. Because CP requires multidisciplinary team efforts to maximize function, comfort, and independence, many therapists, orthotists, and others will interact with

families with a fresh diagnosis of CP. This seminar is intended to provide background and a patient centered approach to discussing diagnosis and treatment options.

**Methods:** Four speakers comprised of a research occupational therapist (AS), two pediatric physiatrists (RS and FR), and one orthotist (KT) will make up the team. AS will reviewing the importance of early diagnosis of CP. RS will then review the tools and resources available to diagnose infants under 2 years and her experience as a pediatric physiatrist at a large tertiary, academically affiliated children's hospital. FR will review the resources and tools used to diagnose CP after two years of age. The approach to delivering the diagnosis of CP to families will then be reviewed by FR and RS using the SPIKES protocol. KT will follow by providing an approach to explaining the role of orthoses, answering difficult questions and overall best practices when considering orthoses in children with CP. Finally, AS will explain some lessons learned from a patient centered outcomes research initiative sponsored CP conference with the goal of determining research priorities in the early diagnosis of CP.

<u>Conclusions</u>: Cerebral palsy is a heterogenous condition that requires input from a multidisciplinary team to allow children thrive to the best of their ability. Audience members will feel comfortable in approaching treatment conversations with families of children with a new diagnosis of CP.
# Advocating for Inpatient Rehabilitation in Pediatric Amputation: Enhancing Recovery and Outcomes

## Gabrielle Nguyen, MD, Marina Ma, MD, Stephanie Miller, DO, and Brittni Willis, PT, DPT

## Short Bio of all Presenting Authors

Dr. Nguyen completed a Fellowship in Physical Medicine and Rehabilitation at Baylor College of Medicine in 2018, following a Residency at the University of Texas Health Science Center - San Antonio in 2016, and earning her Doctor of Medicine degree from The University of Oklahoma in 2012. She is a member of the American Academy of Physical Medicine and Rehabilitation and serve on the Special Interest Group Committee for the American Association of Neuromuscular & Electrodiagnostic Medicine. Dr. Nguyen believes in a multi-disciplinary, collaborative approach to patient care, valuing input from all members of the treatment team, especially the patient and family, with the aim of helping them achieve their maximum functional potential and personal goals.

Dr. Ma completed a Fellowship in Hospice/Palliative Care at Baylor College of Medicine in 2019, a Fellowship in Pediatric Rehabilitation Medicine at Cincinnati Children's Hospital Medical Center in 2018, and a Residency in Pediatric Rehabilitation Medicine at Georgetown University in 2018. Dr. Ma is dedicated to providing high-quality, evidence-based care that is both compassionate and centered around patients and their families.

Dr. Miller completed a Residency in Pediatrics/Physical Medicine and Rehabilitation at Thomas Jefferson University Hospital in 2020. She earned their Doctor of Medicine degree from the Philadelphia College of Osteopathic Medicine in 2014 and a Master of Science from the same institution in 2010. Additionally, Dr. Miller completed a Traditional Rotating Internship at Rowan University School of Osteopathic Medicine in 2015. As a dually-trained rehabilitation medicine physician and pediatrician, her goal is to partner with patients and their families to achieve the best outcomes while collaborating with a multidisciplinary team to ensure all needs are met. Understanding that every child has a unique trajectory and background, Dr. Miller strives to help them find the tools and skills they need to succeed.

Dr. Willis earned a Bachelor of Science in Kinesiology with a focus on Motor Behavior from Texas A&M University in 2012 and a Doctorate of Physical Therapy from the University of Texas Medical Branch in 2015. She is a member of both the American Physical Therapy Association and the Texas Physical Therapy Association. As a physical therapist clinical specialist at Texas Children's Hospital, Dr. Willis evaluates and treats pediatric patients with compassion, striving to promote optimal health and function. She treats each patient as an individual, creating personalized care plans based on their specific functional goals. Committed to staying current with continuing education and research, Dr. Willis provides evidence-based care and leads by example in the workplace.

## Abstract

Amputation presents significant physiological and functional challenges, leading to decreased quality of life and high economic costs. Rehabilitation is essential in promoting functional recovery, improving quality of life, and reducing the financial burden associated with limb loss. Research shows that patients who receive inpatient rehabilitation immediately after acute care achieve superior outcomes, including lower mortality rates, fewer repeat amputations, increased use of prosthetics, and improved medical stability, compared to those discharged home or to skilled nursing facilities.

One of the key advantages of inpatient rehabilitation is access to a comprehensive multidisciplinary team. Surgeons, rehabilitation physicians, psychologists, prosthetists, therapists, and families collaborate closely within the inpatient setting, providing integrated care that addresses both medical and functional needs. This coordinated approach ensures that all aspects of a patient's recovery—physical, emotional, and vocational—are managed effectively. The availability of such a team is a distinct benefit of inpatient rehabilitation, driving better outcomes and a smoother transition to long-term recovery.

Furthermore, extended inpatient rehabilitation has been shown to significantly improve physical function, increase energy levels, reduce pain, and enhance vocational outcomes, underscoring its importance for amputees' long-term recovery.

Through case studies, this symposium will highlight:

- 1. The role of comprehensive inpatient rehabilitation for amputees during both acute and chronic phases.
- 2. The critical collaboration with prosthetists and the wider multidisciplinary team during the inpatient rehabilitation process.

By emphasizing the benefits of multidisciplinary care within an inpatient setting, these discussions will offer valuable insights on optimizing care strategies and improving rehabilitation outcomes for pediatric patients post-amputation.

# Decision-Making in the ICU: Navigating Amputation as a Life-Saving Intervention

### Gabrielle Nguyen, MD, Marina Ma, MD, Stephanie Miller, DO, and Brittni Willis, PT, DPT

#### Short Bio of all Presenting Authors

Dr. Nguyen completed a Fellowship in Physical Medicine and Rehabilitation at Baylor College of Medicine in 2018, following a Residency at the University of Texas Health Science Center - San Antonio in 2016, and earning her Doctor of Medicine degree from The University of Oklahoma in 2012. She is a member of the American Academy of Physical Medicine and Rehabilitation and serve on the Special Interest Group Committee for the American Association of Neuromuscular & Electrodiagnostic Medicine. Dr. Nguyen believes in a multi-disciplinary, collaborative approach to patient care, valuing input from all members of the treatment team, especially the patient and family, with the aim of helping them achieve their maximum functional potential and personal goals.

Dr. Ma completed a Fellowship in Hospice/Palliative Care at Baylor College of Medicine in 2019, a Fellowship in Pediatric Rehabilitation Medicine at Cincinnati Children's Hospital Medical Center in 2018, and a Residency in Pediatric Rehabilitation Medicine at Georgetown University in 2018. Dr. Ma is dedicated to providing high-quality, evidence-based care that is both compassionate and centered around patients and their families.

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Dr. Willis earned a Bachelor of Science in Kinesiology with a focus on Motor Behavior from Texas A&M University in 2012 and a Doctorate of Physical Therapy from the University of Texas Medical Branch in 2015. She is a member of both the American Physical Therapy Association and the Texas Physical Therapy Association. As a physical therapist clinical specialist at Texas Children's Hospital, Dr. Willis evaluates and treats pediatric patients with compassion, striving to promote optimal health and function. She treats each patient as an individual, creating personalized care plans based on their specific functional goals. Committed to staying current with continuing education and research, Dr. Willis provides evidence-based care and leads by example in the workplace.

### Abstract

Considering amputation as a potential life-saving intervention introduces exceptional complexity and uncertainty into decision-making in the ICU. The urgency of critical illness further complicates surgical choices, particularly for patients presenting with severe conditions such as multi-organ failure, infections, or traumatic injuries. This lecture seeks to illuminate the intricate clinical, ethical, and emotional factors influencing the decision to amputate in critically ill patients. By exploring these complexities, we can enhance our understanding of this critical aspect of patient care, ensuring that decisions are made thoughtfully and in the patient's best interest.

This session will adopt a multidisciplinary approach, focusing on patient prognosis assessment and essential discussions regarding quality of life when weighing surgical versus non-surgical options. We will examine the crucial roles of intensivists, surgeons, rehabilitation professionals, palliative care specialists, and families in this high-stakes decision-making process. To illustrate these dynamics, two case studies will be presented, demonstrating how these discussions directly impact surgical decisions and patient outcomes.

#### Key Topics Include:

1. How to Discuss Amputation: Effective communication with patients and their families about the possibility of amputation is essential. These conversations must address fears and uncertainties while providing clear information

about the potential benefits and risks associated with the procedure.

2. **Navigating Ethical Dilemmas:** Ethical considerations are critical in amputation decisions. This session will emphasize the importance of shared decision-making, ensuring that patients' values and preferences are respected while navigating the complexities of care goals.

3. **Managing Postoperative Care and Rehabilitation:** Postoperative care and rehabilitation are paramount after amputation, especially in cases involving multiple limbs. We will discuss pain management, wound care, and the appropriate timing for prosthetic fitting.

4. **Discussing Long-Term Outcomes:** Understanding the long-term implications of amputation is crucial for patient care. We will explore both physical and psychosocial outcomes, considering how amputees adapt to their new realities and the support systems that can facilitate this process.

Through this comprehensive examination, healthcare professionals will gain a framework for making informed, compassionate decisions when faced with complex cases of amputation in the ICU. By enhancing communication among team members and fostering a patient-centered approach, we can improve outcomes and provide better support for both patients and their families during these challenging times.

Ultimately, this lecture aims to equip clinicians with the necessary tools and knowledge to navigate the intricacies of amputation decision-making, ensuring that the care provided is thoughtful, ethical, and aligned with the best interests of critically ill patients.