

## SHRINERS HOSPITALS FOR CHILDREN

A highly skilled medical staff provides first rate care to 1,000 inpatients and over 20,000 outpatient visits annually. The medical staff is comprised of board certified orthopaedic surgeons who are fellowship trained in pediatric orthopaedics, a pediatrician/pediatric rheumatologist, part-time orthopaedic surgeons, and over 90 consulting physicians and surgeons.

Shriners Hospital maintains teaching affiliations with Boston University School of Medicine and Albany Medical College. Additionally, Shriners Hospital provides training to undergraduates and graduate students from area colleges and universities in the fields of nursing, occupational/physical therapy, prosthetics and orthotics, motion analysis, child life and social services.



## SPECIALTY CLINICS

Each weekday children are seen in specialty clinics in the Hospital's Outpatient Department. Specialty clinics are held weekly, bi-monthly or monthly:

- Club Foot
- Developmental Dysplasia of the Hip and Other Hip Disorders
- Legg-Calvé Perthes Disease
- Congenital and Acquired Limb Deficiencies
- Scoliosis and Other Spine Deformities
- Hand Deformities
- Shoulder Deformities
- Osteogenesis Imperfecta
- Juvenile Rheumatoid Arthritis
- Chest Wall Deformities
- Neuromuscular Disorders including Cerebral Palsy
- Myelodysplasia (Spina Bifida)
- Genetic Counseling for Orthopaedic Conditions
- Metabolic Bone Disease
- Cleft Lip and Palate

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## Perception of Care Scores High at Shriners Hospital for Children

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Press Ganey Associates, Inc. provides perception of care surveys for all Shriners Hospitals for Children and thousands of other hospitals nationwide. The most recent Inpatient summary report covered the time period of February 1-July 31, 2005. Patients admitted to the Shriners Hospital for Children gave the facility such high scores that the hospital is now ranked in the top 5 percent of all surveyed hospitals in terms of inpatient satisfaction.

The hospital leadership evaluates these scores as well as verbatim comments from the surveys on a monthly basis. These comments are rich with opportunities for improvement as well as inspiring messages from appreciative families. Greatest improvement in scores was shown in noise level where scores improved 13% over the previous reporting period as well as dietary instructions which improved 3%. Highest satisfaction is documented with "Time the Physician Spent with the Child" with a score of 96, "How Well the Child's Pain Was Controlled" score of 97 and "Skill of Nursing Staff" with a score of 97.

One parent commented, "I felt very safe and informed about all the procedures that were performed on my daughter. It was just a nice comfortable place to be for such a scary surgery. I wish I had known about Shriners Hospital years ago."

The Hospital's outpatient score, for the time period July 1-October 31, 2005 rated over 93 for satisfaction in all major categories. Improving patient flow in the clinic area is an organizational priority. The Hospital's leadership is proud to announce that the greatest improvements in perception scores were documented in ease of scheduling an appointment, ease of registration, and ease for patients in finding their way around the facility. These were areas identified for improvement in previous reports. Many patients are now pre-registered up to a week before their scheduled appointments. This allows patients to come directly to the clinic and bypass the registration area. Escorts are provided for new patients. When a physician calls our clinic with an emergent care issue, the patients usually are seen within 24 to 48 hours. Often, if an appropriate clinician is available and the parents can travel to the hospital, a patient can be seen on the same day as the referral.

A parent noted, "Our waiting time for this visit was only a few minutes at each station. Much better than the previous visit. We (all four of us) love the Shriners Hospital."



## Did You Know...

- Two-thirds of Shriners Hospital patients have health insurance (even though Shriners Hospital does not require insurance)
- 51% of patients come from Massachusetts (the other 49% come from New England, Upstate New York and abroad)
- Any child with an orthopaedic condition under the age of 18 may be referred to Shriners Hospital
- 60% of patients are referred directly by physicians
- Physicians may refer a patient by calling the Chief of Staff at (413) 787-2058 or the Nurse Intake Coordinators at (413) 735-1234
- All care at Shriners Hospital is provided at no cost to families regardless of insurance or financial status
- Shriners Hospitals for Children are the philanthropy of the Shrine Fraternity

**helping kids grow**

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## SAVE THE DATE!

**Tenth Annual  
Bone & Joint Course  
for Pediatricians and  
Family Practice Physicians**

**Thursday, June 1, 2006  
1:00 - 5:30pm  
Lunch - Noon**

For information or registration  
call Rosemary Quigley at  
(413) 787-2027 or email  
rquigley@shrinenet.org

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Did You Know...

## TO REFER A PATIENT

For an appointment or  
to make a referral call  
(413) 735-1234 or  
800-322-5905.

## Clinical Outcomes Assessment of Children with Unilateral Congenital Below Elbow Deficiency

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### Introduction

A unilateral congenital below elbow deficiency (UCBED) is a transverse failure of formation, which occurs when the upper limb fails to form below the elbow. It is the most common level of transverse failure of formation (incidence estimated at 1:20,000 live births) and the level most amenable to prosthetic use. Different types of active prostheses are available; but, the indications for selection of the prosthesis type are not well established. Furthermore, the expectations and goals of children with UCBD and their families frequently differ from the goals of the Prosthetic Team prescribing the prosthesis.

Shriners Hospitals for Children (SHC) serve over 2,000 children with UCBD. Standard care of children with this condition includes evaluation by a multi-disciplinary Limb Deficiency Team, (pediatric orthopaedist, prosthetist, and occupational therapist). Initial fitting with a passive prosthesis occurs when the child can sit, followed by an activated prosthesis when they are 2-4 years of age. There are many different types of prostheses available, ranging in cost from \$300 to \$15,000. Prostheses have never been proven to improve quality of life (QOL) or function for these children, no specific type of prosthesis has been proven superior, and 30-50% of children eventually abandon their prostheses. A cross-sectional study of SHC patients with UCBD, funded by the Clinical Outcomes Studies Advisory Board was initiated to:

- Determine whether use of a prosthesis, prosthesis type, age of first prosthesis fit, adequacy of prosthesis fit, prosthesis training, and prosthesis wear time are associated with satisfaction, quality of life and function for children with UCBD.
- Determine whether child and parent temperament are associated with prosthetic use, satisfaction, QOL and function.
- Determine if satisfaction, function, prosthesis use and QOL correlate with each other.
- Determine if children agree with their parents on assessment tools that are given to both.
- Develop a clinical outcomes assessment protocol for children with UCBD.

To achieve these aims, subjects with UCBD and their parents were tested at ten Shriners Hospitals. Testing included the acquisition of demographic information, and the administration of five computer based touch screen tools and a function test. Touch screen tools included: Prosthetic Satisfaction Index (PSI), Pediatric Orthopaedic Data Collection Instrument (PODCI), Prosthetic Upper Extremity Functional Use Index (PUFI), Peds QL, and Dimensions of Temperament Survey - Revised (DOTS-R).

The function test (UBET), was developed by the UCBD Study Group for the purposes of testing the children with and without their prosthesis, as no such test was available. As part of this project, the UBET has undergone inter- and intra-rater reliability testing. The Completion of Task scale has proven to have very high inter-rater reliability (Spearman  $\rho$  0.98).

A total of 494 subjects and their parents were tested from 2002 to 2004. Study subject ranged in age from 2-21 years and 55% were female. Sixty eight percent chose to wear a prosthesis (wearers); the remainder chose not to wear (non-wearers). Of the wearers tested, 62% used a body powered (BP) prosthesis, 20% used a myoelectric, and 18% used a passive prosthesis.

### Results

#### 1. Use of a Prosthesis

The use of a prosthesis was not found to improve function for children with UCBD, as determined by the PODCI (musculoskeletal health questionnaire) and the UBET (function test). Specifically, there were no significant differences between wearers and non-wearers on any of the six



*“As part of the Demographic questionnaire, non-wearers were asked why they had discontinued the use of a prosthesis; respondents were allowed to give multiple reasons. Of 134 respondents, 56% said that a prosthesis did not help function; 49% said it was uncomfortable, 13% said the child didn't like the appearance of the prosthesis, and 3% responded that the parent didn't like the appearance. Seven percent said they stopped because they were teased, and the same percent found the maintenance burdensome.”*

domains of the PODCI. PODCI Scores for Wearers and Non-Wearers, and wearers using their prosthesis did not perform better on the nine age-appropriate tasks of the UBET when compared with wearers not using their prosthesis or non-wearers.

When wearers and non-wearers were asked how well they performed specific tasks without their prosthesis (PUFI), younger children showed few significant differences between wearers and non-wearers, but older children and adolescent non-wearers reported significantly better performance than wearers with their prosthesis off for every task. However, function testing (UBET) revealed no significant differences between the non-wearers and wearers without their prosthesis.

Furthermore, although children and adolescents with UCBED scored significantly lower than the general population on the Upper Extremity Function domain of the PODCI, and children with UCBED scored lower on the Mobility/Transfer domain, they still score within normal range on these domains, (above the low 80's) and their scores on all other domains are either the same as, or significantly higher than, the general population.

Wearers score significantly higher than non-wearers on quality of life related to Psychosocial Health-School Functioning as measured by the Peds QL. There were no other differences in Peds QL scores between wearers and non-wearers. Compared with the general population, subjects with UCBED and their parents scored higher for Physical Health as measured by the Peds QL.

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## 2. Type of Prosthesis

Function testing (UBET) revealed no differences between wearers age 2-4 years associated with type of prosthesis. Each of the other three age groups showed significant differences associated with prosthesis type for only one of nine tasks. Thus performance was associated with prosthesis type for only three out of 36 tasks. BP wearers performed better on two of these three tasks, and passive prosthesis wearers on one. Myoelectric wearers did not have significantly higher scores for any task.

There were no differences in parent reported Peds QL scores associated with type of prosthesis for children aged 2-4 and 5-7 years. Parents of 8-12 year old passive prosthesis wearers scored their children significantly higher on Physical Functioning than parents of BP wearers. Parents of 13-21 year old BP and myoelectric wearers scored their children higher on Emotional Functioning than parents of passive prosthesis wearers.

For child reported Peds QL scores, there were no significant differences associated with type of prosthesis for 5-7 year olds. Eight to 12 year olds showed mixed results; myoelectric and passive prosthesis wearers reported higher Physical Functioning scores; passive prostheses wearers reported higher Social Functioning scores; and BP wearers reported higher School Functioning scores. For 13-21 year olds, BP wearers had higher scores in all Peds QL domains.

The PSI measures child and parent satisfaction with their prosthesis and the care related to their prosthesis, including fabrication, maintenance and training. BP and myoelectric wearers and their parents were happier with some aspects of their prosthesis and prosthetic care than passive prosthesis wearers.

## 3. Age at First Prosthetic Fit

In general, early fit (< age 2 years) was not associated with higher function scores on the UBET or PODCI. Several PUFI task scores were higher for children fit after age 2 years, but for the majority of PUFI tasks there was no difference associated with age at first fit.

## 4. Prosthetic Training

Training frequency and duration information was difficult to obtain. Many children had some or all of their prosthetic training in the community, and in-house training was not consistently documented. The training information obtained indicated that training was not associated with higher UBET, PUFI or PODCI scores.

## 5. Prosthetic Wear Time

Prosthetic wear time (as reported by the child/parent in hours worn per day) was not associated with higher UBET or PODCI scores. Several PUFI scores were higher for children who reported wearing their prosthesis more than four hours per day.

## 6. Correlation between QOL, Satisfaction, and Function

Objective measurement of function (UBET) scores did not correlate with quality of life as measured by the Peds QL; however satisfaction as measured by the PSI and musculoskeletal health (PODCI) correlated with health related quality of life as measured by the Peds QL.

## 7. Comparison of Children's and Parent's Scores

According to PSI scores, children and adolescents were more satisfied than parents about prosthetic appearance, fit and function, and younger children were less satisfied than parents about how long their prosthesis took to fabricate. On the Peds QL, 5-7 year old children tended to agree with their parent regarding their quality of life; 8-10 year old children agreement was mixed, and 11-21 year olds disagreed with their parents on nearly every domain.

## Clinical Practice Guidelines

Clinical practice guidelines are in development based on the information learned from this multi-center study.

*“BP and myoelectric wearers and their parents were happier with some aspects of their prosthesis and prosthetic care than passive prosthesis wearers.”*



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## Pectus Carinatum

Kevin P. Moriarty, M.D., *Consulting Staff*

An uncommon deformity of the chest wall characterized by anterior protrusion of the sternum and costal cartilages with an approximate prevalence of 1 in 1700 children. It is more common in male than females. Its pathogenesis has been proposed to be congenital in most cases, possibly involving sternal growth plate damage or overgrowth of ribs. Acquired etiologies have also been encountered including drug induced and post-sternotomy. The current correction of this condition is surgical, often involving the resection of costal cartilages and osteotomy of the sternum. The majority of these operations are variations of that first described in 1949 by Dr. Ravitch. In 1979 Drs. Haje and Raymundo from Brazil reported their first experience with nonoperative bracing for the correction of this pectus deformity.

We sought to prospectively investigate this nonoperative modality in children and adolescents presenting with pectus carinatum. This study was done to evaluate the efficacy of nonoperative compression in corrected pectus carinatum in children. It references children presenting with pectus carinatum between August 1999 and January 2004 prospectively enrolled in this study. The management protocol included custom compressive bracing, strengthening exercise, and frequent clinical follow-up. There were 30 children who were entered into this study. The mean age was 13 years – the age range was 3 to 16. There were 26 males and four females. Of the 30 original patients, six never returned to obtain the brace and another four were lost in follow-up. The remaining 20 patients either completed treatment or continued treatment and have been followed as part of this study. The period of bracing was 16 months involving an average of three follow-up visits and two brace adjustments. Five patients had little to no improvement due to either too short follow-up study or noncompliance. Fifteen patients (75%) who were compliant had a significant to complete correction. There were no complications encountered during this study.

## Conclusion

Compressive orthotic bracing is a safe and effective alternative to both invasive surgical correction and no treatment in children with pectus carinatum. Compliance is critical to success of this management strategy.

*Kevin P. Moriarty, M.D. is on the consulting staff at Shriners Hospital for Children. A Chest Wall Deformity Clinic is held once a month in the Hospital's outpatient department.*

