



Shriners
Children's™
Twin Cities

Assessment and Treatment of Pediatric Hand Differences: What's in Your Tool Kit?

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Objectives

Following this presentation, the motivated learner will be able to:

- Identify assessment measures to consider when evaluating a child with a hand difference
- Understand results from several research studies and how they guide clinical decisions
- Describe tool kit options for specialty activities for the wearer and non wearer

Upper Limb Formation



- Begins at 28 days gestation
- Arm and hand structures are mostly formed by 8 weeks

Congenital upper limb deficiencies occur when part of the arm fails to form completely

Longitudinal deficiencies

- Partial or complete absence of an element within the length of the limb
- Commonly associated with other congenital disorders and syndromes
- Radial ray most common which impacts the forearm and thumb side of the hand



Transverse deficiencies

- Can occur at any level from fingers to upper arm
- All elements beyond a certain level are absent
- Limb resembles an amputation stump



<https://www.cdc.gov/ncbddd/birthdefects/ul-limbreductiondefects.html>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6293328/>

Transverse Deficiencies: Failure of formation

- Most common is tranradial or below elbow: upper third level of the forearm (1:30,000 births)
 - followed by transcarpal
 - distal forearm
 - above the elbow / transhumeral
- Non hereditary
- Usually the only impairment
- Almost always unilateral

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6293328/>



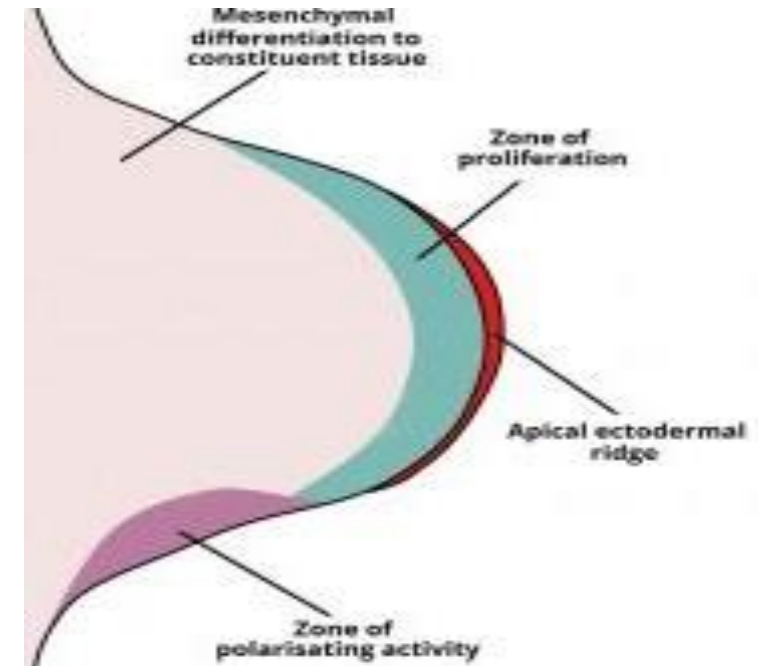
Congenital Transverse Deficiencies

- Cause is most often unknown
- Vascular, due to disruptive events affecting the apical ectodermal ridge (AER) after the limb bud has formed
- Rare incidence includes exposure of the mother to certain chemicals, viruses or medications

**Acquired arm deficiencies in children are rare;
as a result of trauma, tumors or infection*

<https://posna.org/Blogs/The-Resident-Review/July-2017/Transverse-Deficiency>

<https://acpoc.org>



Our hands play an important role in what makes us human

- How we explore the world
- Caress someone you care for
- Communication
- Tool use

Loss of a hand

- Psychosocial and functional implications
- Ability to support objects securely
- Asymmetry in arm length
- Decreased sensory awareness
- Delays with some everyday activities



Emotional reactions for the parent

- Parents may have guilt and sorrow
 - Educate parents: the cause is often unknown, it's not their fault
- “How well a parent accepts the limb deficiency and how well they cope has a great deal to do with how well the child does” *Yoshio Setoguchi MD O & P edge 2005*
 - Kids readily pick up on their parents attitudes, actions and reactions
 - Important to mentor the parent to be on our team
- Social worker can offer counseling for grief, loss and adjustment to the diagnosis



Online resources for support

- shrinerschildrens.org/handdifferences
 - Parent, child and personal experiences
 - Offers support, encouragement and tips in how to differently
- www.helpinghandsgroup.org
- www.limbdifferences.org
- <http://singlehandedsolutions.blogspot.com>
- www.superhands.us
- <http://www.littlefins.org>.



A New Online Resource for parents of children with a **Congenital Hand Difference (CHD)**

Congenital hand differences occur when a child is born with arms and/or hands that look a little different than expected. Children with a CHD will do all of the things they want to do and need to do. This website is here to help!



Visit:

shrinerschildrens.org/handdifferences

Topics featured include:

- Parent Experience
- Child Experience
- Personal Experiences
- School Resources
- Additional Resources
- Pediatric Hand Team

Working in partnership with Michelle James, M.D., chief of orthopaedics, Sarah Tuberty developed the new web page as a capstone project for her Doctorate of Occupational Therapy. Born with Congenital Hand Difference (CHD), Sarah was referred to Shriners Hospital for care at a very young age and is a former patient of Dr. James who helped her develop this website.



Shriners Hospitals
for Children®—Northern California

For more information:
Parents with questions, comments or concerns regarding Congenital Hand Difference (CHD) are encouraged to contact the Northern California hand team. Please email us at ncl.chd@shrinenet.org



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Family education: Share clinical experience and past research

- Child will find a way to do nearly everything
- Study findings on quality of life and happiness
- Prosthetic options and tools for their tool kit



Successful care requires a multi-disciplinary approach tailored to the individual: prosthetic fitting, rehabilitation services, social work

- Orthopedic Surgeon
- Physician Assistant
- Nurse
- Social Worker
- Occupational and Physical Therapist
- Orthotist and Prosthetist
- Radiologist



Goals of Occupational Therapy

- Assist with social acceptance and confidence
- Family education: best practice
- Optimize child's participation in everyday activities
- Prosthetic and activity of daily living (ADL) training
- Develop arm strength and function



Study: Prosthetic Preferences

Crandall RC, Tomhave W. Pediatric unilateral below-elbow amputees: retrospective analysis of 34 patients given multiple prosthetic options. J Pediatr Orthop. 2002 May-Jun;22(3):380-3.

Purpose:

Understand what type of prosthesis is preferred over time when given the option with three different styles in children with UCBED

Design / methods:

Chart reviews of 34 children considered good prosthetic wearers.

Questionnaire asking about prosthesis preferences for 22 activities.

Most had been fit with:

- Passive hand (100%)
- Body-powered prosthesis (97%)
- Myoelectric prosthesis (82%)

Study: What style of prosthesis was most preferred?

Passive hand: 44%

Lightweight

No harness

Cosmetic value



Body Powered: 41%

Harness / cable to activate the hand

Durable, lightweight

Functional value



Myoelectric: 15%

Hand is activated using muscle movement from the forearm

Cosmetic and functional

Higher maintenance



Study: Prosthetic Preferences

In long term follow up 41% of patients continued as multiple users



Study: Prosthetic Preferences Conclusions

- The most preferred prosthesis is simple, durable and light weight
- Subjects selected the body-powered prosthesis most often when asked about which style of prosthesis they preferred for 22 functional activities
- Successful users may choose multiple prostheses on the basis of function
- It's important to base your practice on evidence and to share key findings with your patients to help them make decisions about their care



Study: Impact of prosthesis on quality of life and function

- Shriners Hospitals system served over 2,000 children with unilateral congenital below elbow deficiency in 2005
- Prescription of a prosthesis was common practice
- Prosthesis rejection 40%
- No prior research to measure prosthesis function
- 10 Shriners hospitals joined to develop evidence based guidelines
- The major aim was to determine if a prosthesis is associated with a better quality of life and function

- Enrolled 489 children – 2 hours of testing
- 321 wore a prosthesis, 67 non-wearers



James MA, Bagley AM, Brasington K, Lutz C, McConnell S, Molitor F. Impact of prosthesis on function and quality of life for children with unilateral congenital below elbow deficiency. J Bone Joint Surg AM. 2006 Nov;88(11):2356-65

Study: Impact of prosthesis on function and quality of life

Standardized Outcome measures

- **PedsQL- Quality of Life Survey**

How much of a problem they have in the areas of:

- Physical - Social
- Emotional - School functioning

- **Pediatric Outcomes Data Collection Instrument (PODCI): musculoskeletal health:**

- mobility - physical activity - pain / comfort - global function
- upper extremity function - sports - happiness

- **Unilateral below elbow test (UBET):**

Designed and validated for this study to measure how a child functions with and without a prosthesis

The Unilateral Below Elbow Test

Bagley AM, Molitor F., Wagner L., Tomhave W., James M. *The Unilateral Below Elbow Test: a function test for children with unilateral congenital below elbow deficiency.* Dev Med Child Neurol. 2006 Jul, 48(7):569-575

Nine different tasks for 4 different age groups

Measures how well they perform the task and the what method of object stabilization is used

If a child wore a prosthesis they were tested twice – with and without



Study: Impact of prosthesis on function and quality of life

Conclusions:

- Children with below elbow deficiency have a near normal quality of life and scored the same as or higher than the general population on the PedsQL
- They scored themselves significantly lower on the PODCI upper extremity physical function domain
- PODCI happiness scale they scored themselves higher than the general population
- UBET function test: Non wearers performed the same as or better than the wearers; good function regardless of prosthesis wear

Clinical Experience: Fitting a child with a prosthesis

- Never know who will be a good wearer and user
- Early fitting is beneficial
- A prosthesis in young children can assist in gross and fine motor development
- A child's needs change over time. There may be indication for a specialty tool .
- Advances in myoelectrics: multiple grasp styles as well as cosmetic value



Assessment

- Prosthetic wear history
- Learn about the child's and family's goals and expectations
 - concerns / functional limitations
- Abilihand's questionnaire- perceived ability for 21 activities
- Observe arm function with tasks that require grasp and stabilization
 - Bimanual toy kits, UBET tasks



Toy kits to evaluate arm function

(4 kits: infant, toddler, school age and teenager)

Bimanual interesting toys of different size and feature

- musical instruments
- hand crack music box
- wooden stick / pop up puppet
- kaleidoscope
- pull string vibrating toys
- pull apart toys
- bead stringing
- writing / scissors
- playdough
- toys with lights and sound



Transhumeral (Above elbow) functional challenges

- scapular and shoulder movements
- methods of stabilizing are against the trunk / knees / chin
- limited midline play
- asymmetrical arm reach head / feet

Prosthesis beneficial but challenging:

- weight of the arm
- positioning in space
- enables a secure grip at midline
- friction elbow for young users



Transradial / below elbow length of forearm

- most common length seen here on the left
- elbow grasp huge functional advantage
- short forearm impacts methods for stabilizing



Transcarpal; wrist movement

- wrist cupping a big functional advantage
- long forearm good midline abilities and sensibility so rejection rate high
- benefit from tools for a secure grasp, weightbearing



Infant considerations

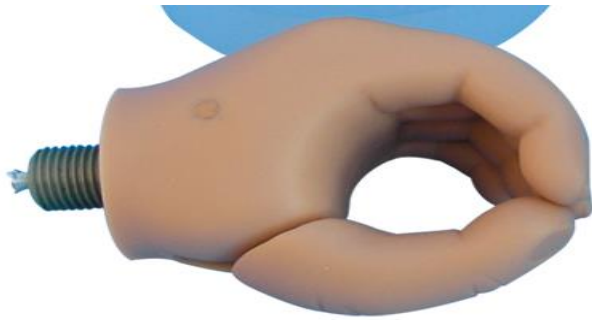
Your patient is the parent!

- Parental acceptance and reassurance
- Gross motor skills progress close to normal
- Arm use – parent support to encourage weight bearing, reach, toys for bimanual play



Early fitting of a prosthesis

- Children fitted with first prosthesis before age two have lower rejection rates
- Fitting guided by clinical experience and parent motivation
- First passive prosthesis: Lil – EZ feed hand 12-18 months



Farr S, Catena N, Martinez-Alvarez S, Soldado F; EPOS Upper Limb Study Group. J Child Orthop. 2018 Dec 1;12(6):558-565. doi: 10.1302/1863-2548.12.180107. PMID: 30607202

Toddler / Preschool

Cognitive and motor skill development may bring need for a new tool

- Parent concerns may include:
 - Inability to play with toys at midline or stabilize objects well
 - Unequal arm length can cause difficulties:
 - pushing a toy grocery cart
 - steering a bike
 - hand stands
- Education
 - Prosthesis options and clinical recommendations



Body-Powered Voluntary Opening Prosthesis ***18 months – 2 1/2***



Body-Powered Voluntary Closing Prosthesis

- Convert the terminal device to voluntary closing ages 2 ½ - 3
- Two choices depending on goals for function and cosmesis



ADEPT Terminal Device



Lite Touch Terminal Device

Myoelectric prosthesis

- combine cosmetic look of a hand with function
- multiple grasp styles
- no harness
- motivation for new technology



What to Expect with a Prosthesis: Ages 3-4

- Donn/doff the prosthesis
- Activate the terminal device
- Perform most ADLs
- Can explain their hand difference



Encourage positive self esteem and self acceptance

- Self esteem comes from being loved and feeling secure
- Parenting tips to build their child's self esteem
- Child wants to be treated like anyone else
- Help the child find words to explain their hand difference
- Teacher resources: tips for success in the classroom



[shrinerschildrens.org/handdifferences](https://www.shrinerschildrens.org/handdifferences)

<https://www.todaysparent.com/family/parenting/how-to-build-your-childs-self-esteem/>

Books for Children with Hand Differences

- The Making of My Special Hand: Madison's Story *Jamee Heelan*
- Uniquely Me! *Trace Wilson*
- Different Is Awesome! *Ryan Haack*
- God Made Me Special, Just Like You! *Nicki Olin*
- Little Arm and Me *Mutiya Vision*
- What's the Matter with Henry? The True Tale of a Three-legged Cat *Cathy Conheim*
- Handbook for Dragon Slayers *Merrie Haskell*
- One-Handed Catch *Mary Jane Auch*
- Amputeddy Goes Back to School (book series) *Jean Boelter*



School age: Concerns become more focused

- ADLs –fasteners, ponytails, cutting foods
- Jumping rope
- Riding a bike
- Keyboarding



School aged: Shoe tying most requested concern

Loop method

- 1. Push string back through hole and tie a small knot*
- 2. Take two loops and tie a knot*
- 3. Take those two loops and tie a second knot (makes a secure tight double knot with easy loops to hold)*



Occupational Therapy

Upper limb prosthetic training

- Basic componentry
- Donning / doffing
- Body movements to open/close the hand
- Grasp / release with puzzle board
- Age appropriate activities:
 school, ADLs, gross/fine motor skills



Mano H., Fujiwara S., Haga N. Effect of prosthesis on children with congenital upper limb deficiencies. Pediatr Int. 2020 April 23

Upper Extremity Prosthetic Training Activities



▣ Wearing Schedule

Establish a wearing schedule for your child. Put the prosthesis on your child ___ times each day for ___ hours to get your child used to it. Gradually increase the wearing time to full time.

As your child wears the prosthesis, he will become aware of the benefits of his new arm.

You may need to guide your child's arms to help with opening and closing the terminal device. Help your child during play activities (short periods) to position and place objects in the prosthesis.

Work in front of a mirror to help your child see how to work the terminal device.

If your child has any redness that does not go away after 20-30 minutes, please call your prosthetist.

▣ Indoor Play Activities

- Stringing large beads
- Sewing cards
- Work bench with toy screws
- Fishing pole
- Musical instruments: cymbals, blocks, triangle, drums
- Tea party: carrying tray, washing and drying dishes, feeding dolls
- Dressing dolls

- Cooking: rolling dough, stirring food
- Plastic containers and lids
- Play telephone
- Jack-in-the-box
- Legos or Duplos
- Pop-beads
- Cutting with scissors (hold paper with prosthesis)
- Coloring books/paper (use prosthesis to stabilize coloring book/paper)

▣ Outdoor Play Activities

- Tricycle
- Swing
- Slides
- Large balls
- Child size gardening tools
- Push toys

▣ Self-Care Activities

- Beginning dressing skills - T-shirt on/off, pulling pants up/down
- Toileting - Pushing down and pulling up clothing
- Brushing teeth - Putting toothpaste on toothbrush
- Washing face and other hand

Follow up assessment

- Patients are seen by the physician every 6 months
- Prosthesis - evaluate the condition, proficiency
- Assess new interests and concerns



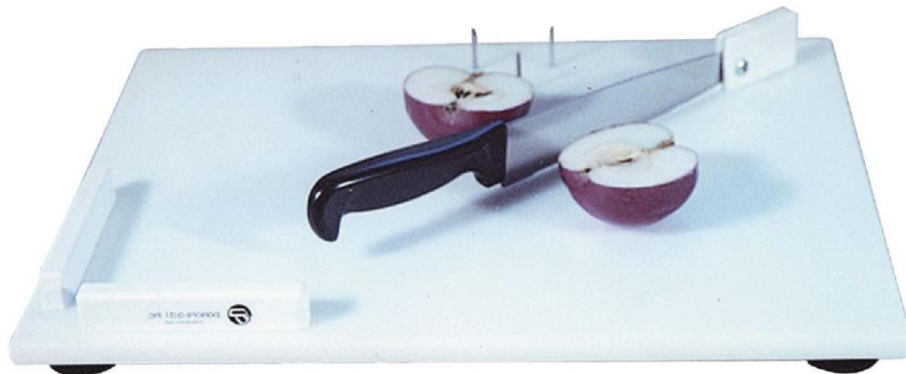
Life brings change: what's in your tool set

- weight lifting
- hunting
- four wheeling
- fishing
- kayaking



OT may provide adaptive devices ***Food preparation***

- Food scrubber
- Electric can opener
- One handed rolling pin
- Adaptive cutting boards
- Rocker style knives



Activity specific tools

Musical instruments



Sports Prostheses

- Passive sports prosthesis
- Basketball
- Hockey
- Gymnastics
- Baseball
- Golf



Winter and summer camps at Shriner's

- Shriners Children's Twin Cities offers specialty camps for children with limb differences
- Exposes kids to new experiences
- Allows for special friendships and support for both kids and parents
- Contact mjohnson@shrinenet.org for camp dates and programming



Summary

- Very few activities a child is unable to perform with transverse deficiency if they have one sound hand
- Strive to understand a child's special interests and activities; there may be a tool to assist them
- Nurturing and educating families is key to adjustment and a child's success
- Research and clinical experience helps guide current practice

THANK YOU!

