

## Congenital Limb Difference

January 2006

People with limb loss have particular information needs. *Topic of the Month* is a resource guide of information relevant to amputees. Click on the links below to access articles and Web sites directly. Many of the books and videos can be borrowed through [Interlibrary Loan](#).

Many more resources can be found by searching our [online library](#). Please feel free to share this resource with those who may find this useful. We also welcome your comments and topic suggestions! Contact us via e-mail at [library@amputee-coalition.org](mailto:library@amputee-coalition.org).

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*inMotion* & *First Step* Articles  
Fact Sheets  
PubMed® Abstracts  
Videos  
Web Sites, Organizations &  
Electronic Resources

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## Books

**Atlas of Amputations and Limb Deficiencies: Surgical, Prosthetic, and Rehabilitation Principles** / American Academy of Orthopaedic Surgeons; edited by Douglas G. Smith, John W. Michael, and John H. Bowker. 3rd edition. Rosemont, IL: American Academy of Orthopaedic Surgeons, 2004. ISBN 0-89203-313-4. This atlas is a comprehensive reference on the surgical, prosthetic and rehabilitative management of adults and children who have lost a limb or who have congenital limb loss. This source contains many images and illustrations.

**The Child With a Limb Deficiency: A Guide for Parents** / by Darlene Talbot. Los Angeles: Child Amputee Prosthetics Project, Univ. of California at Los Angeles, c1979. This book offers support and general guidelines for handling common concerns in rearing a child with a limb deficiency.

**The Child With a Limb Deficiency** / edited by John A. Herring and John G. Birch . 1st ed. Rosemont, IL: American Academy of Orthopaedic Surgeons, c1998. ISBN 0-89203-175-1. This book is a collection of several papers regarding limb deficiency and children. The subjects include amputation, rehabilitation and recreational activities.

**Children With Limb Differences: A Handbook for Families (Ages Birth to Five Years )** / Nancy Bradley ... [et al.]. 3rd revised edition. Grand Rapids, MI: Center for Limb Differences, 2003. This booklet is for parents of limb-different children from birth to five years old. It provides a guide to normal growth and development, including a section on starting school. It contains basic information on types of limb loss, medical care and treatment issues, and prosthetic options. There is also information about financial and educational resources.

**Who is Amelia? : Caring for Children With Limb Deficiencies** / Hugh G. Watts and Mary Williams Clark.

Rosemont, IL: American Academy of Orthopaedic Surgeons, 1998. ISBN 0-89203-179-4. This book is written by two distinguished physicians who treat pediatric patients with congenital limb difference. This book is designed to help physicians increase their awareness and comfort level when faced with the uniqueness of their own patients and the special care needed to help these children and their families cope.

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## ***First Step and inMotion Articles***

**“Alternatives: Life Without Artificial Limbs”** / Jan Garrett. Knoxville, TN: Amputee Coalition of America, 1998. *inMotion*, January / February 1998. Jan Garrett, who has a congenital absence of all four limbs, discusses adaptive alternatives to artificial limbs and solicits reader ideas.

[http://www.amputee-coalition.org/inmotion/jan\\_feb\\_98/lfwolmb.html](http://www.amputee-coalition.org/inmotion/jan_feb_98/lfwolmb.html)

**“Alternatives: Life Without Artificial Limbs: Relationships: the Perfect Match”** / Jan Garrett. Knoxville, TN: Amputee Coalition of America, 1998. *inMotion*, November / December 1998. Jan Garrett, who has a congenital absence of all four limbs, discusses how the support of her family offered a solid foundation for future relationships.

[http://www.amputee-coalition.org/inmotion/nov\\_dec\\_98/altern.html](http://www.amputee-coalition.org/inmotion/nov_dec_98/altern.html)

**“Facing Amputation Surgery: Early Fitting is Key to Success”** / Diane Atkins. Knoxville, TN: Amputee Coalition of America, 2001. *First Step: A Guide for Adapting to Limb Loss*, 2001. This article looks at the importance of fitting children with congenital limb differences early in life for a prosthesis.

[http://www.amputee-coalition.org/first\\_step/firststepv2\\_s1a13.html](http://www.amputee-coalition.org/first_step/firststepv2_s1a13.html)

**“Facing Amputation Surgery: Facing Congenital Limb Differences: A Child is More Than an Arm or a Leg”** / Rick Bowers. Knoxville, TN: Amputee Coalition of America, 2001. *First Step: A Guide for Adapting to Limb Loss*, 2001. This article looks at the challenges of parenting a child with limb differences.

[http://www.amputee-coalition.org/first\\_step/firststepv2\\_s1a12.html](http://www.amputee-coalition.org/first_step/firststepv2_s1a12.html)

[http://www.amputee-coalition.org/spanish/first\\_step/firststepv2\\_congenital\\_differences.html](http://www.amputee-coalition.org/spanish/first_step/firststepv2_congenital_differences.html)

**“My Little Miracle”** / Isabel Pereiras. Knoxville, TN: Amputee Coalition of America, 2001. *inMotion*, September / October 2001. Isabel Pereiras discusses having a child with a limb difference. Her advice for anyone with a special child is to always tell them the truth when asked a question, love them just the way they are, help them learn to love and accept their body, encourage them to see the positives in life, and never dwell on their differences.

[http://www.amputee-coalition.org/inmotion/sep\\_oct\\_01/miracle.html](http://www.amputee-coalition.org/inmotion/sep_oct_01/miracle.html)

[http://www.amputee-coalition.org/inmotion/sep\\_oct\\_01/miracle.pdf](http://www.amputee-coalition.org/inmotion/sep_oct_01/miracle.pdf)

**“Standing Out in the Crowd”** / Rick Bowers. Knoxville, TN: Amputee Coalition of America, 2001. *inMotion*, November / December 2001. This article looks at the story of Jessica Cox. Jessica was born without arms, but hasn't let that keep her from doing the things she wants to do in life.

[http://www.amputee-coalition.org/inmotion/nov\\_dec\\_01/standing.html](http://www.amputee-coalition.org/inmotion/nov_dec_01/standing.html)

[http://www.amputee-coalition.org/inmotion/nov\\_dec\\_01/standing.pdf](http://www.amputee-coalition.org/inmotion/nov_dec_01/standing.pdf)

**“Support Groups Are Key: A Parent's Perspective on Pediatric Prostheses”** / Barbara Clark. Knoxville, TN: Amputee Coalition of America, 1995. *inMotion*, Fall 1995. Born without her left hand, Stephanie Clark was fit with a passive prosthesis at three months. At 26 months, she received a myoelectric hand. Stephanie was also responsible for forming a thriving support group for people with congenital limb differences.

[http://www.amputee-coalition.org/inmotion/fall\\_95/parentper.html](http://www.amputee-coalition.org/inmotion/fall_95/parentper.html)

[http://www.amputee-coalition.org/inmotion/fall\\_95/parentper.pdf](http://www.amputee-coalition.org/inmotion/fall_95/parentper.pdf)

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## Fact Sheets

**“NLLIC / ACA Fact Sheet: Limb Differences – Definitions ”** / Amputee Coalition of America ... [et al.]. Knoxville , TN: Amputee Coalition of America, 2003. This fact sheet presents an extensive list of terms relating to limb differences and amputation.

[http://www.amputee-coalition.org/fact\\_sheets/definitions.html](http://www.amputee-coalition.org/fact_sheets/definitions.html)

[http://www.amputee-coalition.org/fact\\_sheets/definitions.pdf](http://www.amputee-coalition.org/fact_sheets/definitions.pdf)

[http://www.amputee-coalition.org/spanish/fact\\_sheets/definitions.html](http://www.amputee-coalition.org/spanish/fact_sheets/definitions.html)

[http://www.amputee-coalition.org/spanish/fact\\_sheets/definitions.pdf](http://www.amputee-coalition.org/spanish/fact_sheets/definitions.pdf)

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## PubMed ® Abstracts

**“Epidemiology of Limb Loss and Congenital Limb Difference: A Review of the Literature”** / PL Ephraim ... [et al.]. Philadelphia, PA: WB Saunders, 2003. *Archives of Physical Medicine and Rehabilitation*. 2003 May; 84(5):747-61.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?>

[cmd=Retrieve&db=PubMed&list\\_uids=12736892&dopt=Abstract](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12736892&dopt=Abstract)

**“Lower Extremity Abnormalities in Children”** / P. Sass and G. Hassan. Kansas City, MO: American Academy of Family Physicians, 2003. *American Family Physician*. 2003 Aug 1; 68(3):461-8.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?>

[cmd=Retrieve&db=PubMed&list\\_uids=12924829&dopt=Abstract](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12924829&dopt=Abstract)

**“Major Lower Limb Congenital Shortening: A Mini Review”** / JA Fixsen. Hagerstown, MD: Lippincott Williams & Wilkins, 2003. *Journal of Pediatric Orthopaedics*. Part B. 2003 Jan; 12(1):1-12.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?>

[cmd=Retrieve&db=PubMed&list\\_uids=12488764&dopt=Abstract](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12488764&dopt=Abstract)

**“The Pediatric Outcomes Data Collection Instrument (PODCI) and Functional Assessment of Patients with Unilateral Upper Extremity Deficiencies”** / JA Lerman ... [et al.]. New York: Raven Press, 2005. *Journal of Pediatric Orthopaedics*. 2005 May-Jun; 25(3):405-7.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?>

[cmd=Retrieve&db=pubmed&dopt=Abstract&list\\_uids=15832164](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15832164)

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## Video

**Walk This Way** / A Kathryn Vander film, made in association with Walk This Way Productions. Boston, MA:

Fanlight Productions, 1998. ISBN 1-57295-271-7. Born with a congenital limb difference, Ron Bachman had his legs amputated when he was four. He learned to walk on his hands and with prosthetic legs. He eventually gave up the prostheses, and decided to follow his own lifestyle and pursue his own ambitions.

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## Web Sites/Organizations & Electronic Resources

**Association of Children's Prosthetic-Orthotic Clinics (ACPOC).** Rosemont, IL: ACPOC, 2001. ACPOC is an association of professionals who are involved in clinics that provide prosthetic-orthotic care for children with limb loss or orthopaedic disabilities.

<http://www.acpoc.org>

**Genetic and Rare Diseases Information Center / Office of Rare Diseases, National Institutes of Health .** Gaithersburg, MD: Office of Rare Diseases, National Institutes of Health, 2003-. Established by the National Human Genome Research Institute (NHGRI) and the Office of Rare Diseases (ORD), the Genetic and Rare Diseases Information Center employs experienced information specialists to answer in English or Spanish questions from the general public, including patients and their families, healthcare professionals and biomedical researchers.

[http://rarediseases.info.nih.gov/html/resources/info\\_cntr.html](http://rarediseases.info.nih.gov/html/resources/info_cntr.html)

**Helping Hands Foundation.** Medfield, MA: Helping Hands Foundation, 2002-. Helping Hands Foundation, Inc. is a nonprofit support group made up of parents who have children with upper limb differences and who are concerned with the challenges facing the child and his or her family.

<http://www.helpinghandsgroup.org>

**International Child Amputee Network- I-CAN!** / Bill Baughn. [S.l.: s.n.], 1996-. This Web site presents information about an Internet mailing list that provides information and support contacts to children with absent or underdeveloped limbs and their parents.

<http://child-amputee.net/Bill/billbaughn.htm>

**LimbDifferences.org: An Online Resource for Families and Friends of Children With Limb Differences.** [ United States]: LimbDifferences.org, 2002-. This site is a continuation of the now-archived Super-kids.org Web site and newsletter. The site aims to provide practical information as well as emotional support for families and friends of children with limb differences.

<http://www.limbdifferences.org>

**March of Dimes.** White Plains , NY : March of Dimes, 2002-. The mission of the March of Dimes is to improve the health of babies by preventing birth defects and infant mortality.

<http://www.marchofdimes.com>

**National Organization of Rare Diseases (NORD)** , Danbury, CT: National Organization of Rare Diseases, 2002-. NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and service.

<http://www.rarediseases.org>

**SuperHands: For Kids and Adults With Hand and Upper Limb Differences** / developed by Steve Geigle. [ United States: s.n., 199-]-. SuperHands is a forum to learn about and network with adults and youth who have hand or upper limb differences.



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