

# NAVIGATING LIMB DIFFERENCES

A PARENT'S COMPANION

Introduction

FAQ

Supportive Communities

Communication

Adaptive Tools

Inclusive Products



**LIMB DIFFERENCE  
COLLECTIVE  
FOUNDATION**

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# Welcome



Whether you're preparing for your child's arrival, or have already welcomed them into the world, we're happy you're here. We remember the moment we first learned our children had a limb difference—full of questions, unsure where to turn, and longing for one place that offered clarity, hope, and connection.

That's why we created this organization. We believe every family deserves compassionate support and practical tools. This booklet is one of them - designed to meet you where you are, whether you're just beginning this journey or supporting someone who is.

Inside, you'll find answers to common questions, tips for siblings and caregivers, and resources that reflect and celebrate difference. These are the kinds of tools we wish we had in those first days - honest, comforting, and rooted in lived experience.

Start wherever feels right. Each page offers insights from families who've walked this path before you. We've included references to products and communities that we and others have found helpful, though we're not formally affiliated unless noted.

For the latest updates, visit [limbdifferencecollective.org](https://limbdifferencecollective.org). And remember: no single guide holds every answer. What you will find here is a community cheering for your child's unique strengths - and ready to lift you up through any challenge.

Obstacles may arise, but within these pages lies a roadmap of possibilities. We hope you find encouragement, connection, and joy in every milestone - big or small.

With Hope, Understanding, Growth, and Support

Ali & Kari

Co-Founders of the Limb Difference Collective Foundation

A Gentle Reminder: This booklet is not a substitute for medical advice, diagnosis, or professional counseling. We are not medical professionals, and the information shared here is based on lived experience and community wisdom. If you or your child need medical, psychological, or therapeutic support, we encourage you to reach out to a licensed professional.

What is a

# Limb Difference?

A limb difference describes any condition in which a portion of an arm or leg is missing or under-developed. These differences may be:

- Congenital: Present at birth
- Acquired: Amputation or loss due to injury, illness, or medical treatment

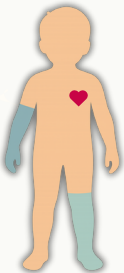
## Common Types of Congenital Limb Differences

### Upper-Limb Differences

- Transverse Deficiency: The limb is absent beyond a certain point (e.g., upper arm ends at elbow, forearm ends at wrist)
- Longitudinal Deficiency: One bone in the forearm or upper arm is partially or completely missing: ex. radial aplasia (radius bone absent or under-developed)
- Ulnar deficiency: ulna bone missing/shortened
- Symbrachydactyly: Short, webbed, or fused fingers
- Polydactyly: More than five fingers on one hand
- Ectrodactyly (“Split Hand/Foot”): Middle digits missing, creating a cleft appearance
- Phocomelia: Hands or feet attach close to the trunk, limb segments very short

### Lower-Limb Differences

- Limb Length Discrepancy: One limb is shorter than the other
- Fibular Hemimelia: Partial or complete absence of the fibula bone (shin)
- Tibial Hemimelia: Tibia bone is partially or fully missing; foot may attach directly to thigh
- Clubfoot (Talipes Equinovarus): Foot turns inward or downward (may be associated with limb-length differences)



Some limb differences may require medical interventions, others might not. Information provided by medical professionals, and through lived experiences throughout the community can be beneficial in planning for your child's care. Ultimately, you as a parent know what's best for your child based on the information you receive.

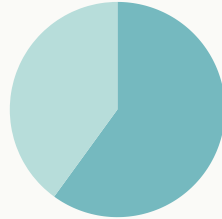
Source: [childrenshospital.org/conditions/congenital-limb-differences](https://childrenshospital.org/conditions/congenital-limb-differences)

# Facts & Stats



1 in  
1,900

Children  
are born  
with limb  
differences  
each year



60%

of amputations  
are congenital

40% are acquired amputations

61%

involve the arms,  
hands or fingers

39% affect the legs feet or toes

5.6 million

Americans live with limb loss or  
limb difference

2.3 million

people have experienced limb loss

3.4 million

individuals live with limb difference

Sources:

Centers for Disease Control and Prevention (CDC)

Amputee Coalition

National Institute of Health (NIH)

American Society for Surgery of the Hand (ASSH)

Annually, there are about

500,000

new cases of limb loss or limb  
difference in the U.S.

While these numbers may surprise you, they also mean one thing: you're not alone. A vibrant community stands ready to support, encourage, and share every step of the journey.

# Frequently Asked Questions

## Why did this happen?

Most congenital limb differences occur randomly and without a clear cause. They can result from early disruptions in limb development, vascular issues, or conditions like Amniotic Band Syndrome. In most cases, it's not the result of anything you did or didn't do during pregnancy.

## Will this happen again in future pregnancies?

The chance of recurrence is typically very low. Most congenital limb differences aren't hereditary. However, your healthcare team or a genetic counselor can offer personalized guidance based on your family history and test results.

## Will my child need a prosthetic?

Some children benefit from prosthetics, while others thrive without them. It depends on their specific limb difference, developmental stage, and personal preferences. Focus on what works best for your child - not what's typical.

## Can my child play sports or other activities?

Kids with limb differences participate in countless sports, music and hobbies. It may take creativity and modifications, but nothing should be off-limits.

## I feel overwhelmed.

You're not alone. It's okay to have big feelings. We created this guide and are growing Wolf Pack community to lift each other up with Hope, Understanding, Growth and Support—every step of the way.

## Will my child be okay?

Children with limb differences can grow up to lead full, joyful lives. Some may need medical interventions, adaptive tools or therapies, but their creativity, confidence, and independence often flourish with the right support and community.

## Should we see a specialist?

Connecting with a pediatric orthopedic specialist, occupational therapist, or prosthetics team, early, can help guide treatment and build a support plan. You can also explore community-led resources for emotional and peer support.

## How do we discuss with doctors and educators?

Be proactive - share this booklet, ask questions, and advocate for inclusive solutions. Many professionals appreciate your perspective and will work with you to support your child's unique needs.

## How do we explain this to friends or siblings?

With honesty and positivity. Many families use simple phrases like "She was born with a difference in her arm, and she does things in her own unique way." Including siblings in conversations fosters understanding and pride.

## Where can we meet other families like ours?

Check the section of Supportive Communities & Online Groups. You'll find family meetups, private Facebook groups, nonprofit networks, and local events designed just for you.

# Important Dates & Awareness Celebrations

Mark these dates to honor lived experiences, amplify awareness, and celebrate you and your child

February 27/28	<b>Rare Disease Day</b> Honors rare conditions and the families navigating them.
April	<b>Limb Loss &amp; Limb Difference Awareness Month (LLLDAM)</b> Celebrates identity, resilience, and advocacy.
3rd Thursday of May	<b>Global Accessibility Awareness Day (GAAD)</b> Promotes digital inclusion and access.
July	<b>Disability Awareness Month</b> Elevates disability pride and visibility.
July 26	<b>National Disability Independence Day</b> Marks the signing of the ADA in 1990.
Last Week of September	<b>National Inclusion Week</b> Spotlights inclusive practices and belonging.
October	<b>Disability Employment Awareness Month</b> Honors contributions and equity in the workplace.
Tuesday after Thanksgiving	<b>Giving Tuesday</b> A global day of generosity and impact.
December 3	<b>International Day of Persons with Disabilities</b> Advocates for dignity, rights, and inclusion.
Birthdays	<b>Celebrate you and your child</b> The day you brought something beautifully unique into the world.
Ampuversary	<b>Honor the Journey</b> A personal milestone—reflect, celebrate, or simply acknowledge strength and growth.

Please visit our website for a calendar listing the dates and events being hosted throughout the country

# Sibling & Family Support

Every family is unique, and every child brings something extraordinary to the table. Whether your child was born with a limb difference or experienced an amputation, this journey is shared - and siblings, parents, and caregivers all play a role in shaping a loving, inclusive home.



## Normalize Curiosity

- Encourage siblings to ask questions openly.
- Offer age-appropriate explanations and spark conversation
- Use books, toys, or videos



## Celebrate Each Child's Strengths

- Remind family members that everyone has differences, and strengths
- Create rituals that highlight each child's talents and milestones

"We're proud of how you help your brother/cousin feel strong."



## Build Inclusive Language & Stories

- Teach siblings respectful ways to talk about limb differences
- Practice short, confident responses

"My sister was born with one hand, and she's amazing at drawing!"

- Share books with family focus



## Create Safe Spaces for Big Feelings

- Acknowledge that siblings may feel confused, jealous, protective, or even left out.
- Plan one-on-one time, journaling prompts, or find sibling support groups.



## Grow Together as a Family

- Invite siblings to help pack prosthetic bags, choose adaptive toys, or decorate awareness posters
- Include them in hospital visits or therapy sessions when appropriate

## Affirm the Whole Family

"I am a kind and curious sibling."  
"Our family celebrates differences."  
"We grow stronger together."

# School & Activity Introductions

Some families choose to introduce their child and families to new environments in creative ways. From parent & me classes to guest readers, providing information in advance can help a teacher, staff, or coach assist with fielding questions or using proper language if peers are curious, but may not be ready to speak about themselves.

**Hello**  
my name is

Things I'm good at:

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I Call My Limb Difference

Things I might need help with:

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When someone asks about my limb difference, I tell them:

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Here are some examples of details you can include:

“This is the way I was made” “It’s what makes me unique” “I can do most anything others can do, sometimes just a little bit differently”

Some families have found open communication to be a great tool in helping their child form a positive narrative surrounding this part of them that makes up their whole person. Other families may choose to limit what they share and let the child take the lead on each conversation, too!

# Books & Media Representation

Stories have the power to shape how we see ourselves and others. Whether it's a book that reflects your child's experience, a show that sparks conversation, or a podcast that uplifts disabled voices—this page is a starting point for joyful, inclusive media.

## Books



### **Different is Awesome** by Ryan Haack

A boy introduces his brother—born with one hand—during show-and-tell, helping kids discover that everyone's differences make them unique, capable, and truly awesome.



### **The Able Fables Series** by Dr. Nicole Julia

Inclusive books featuring disabled characters pursuing their dreams. Each story promotes self-worth and belonging. "Goldie's Tasty Tacos" features a character with a limb difference.

### **What Happened to You?** by James Catchpole

A funny, honest picture book that empowers kids to set boundaries, while helping others understand that curiosity doesn't always need an answer - sometimes, play is the best response.



### **The Capables Series** by Danny Jordan

Superhero stories starring kids with disabilities. Rae's First Day is the first book in the series. Created by a dad for his daughter with a limb difference.



## Shows



### **Robo Gobo Go** (Disney+)

Dax, a brilliant young inventor with a limb difference and a high-tech prosthetic, leads a team of rescue pets to save animals and show kids that heroes come in all shapes, sizes, and abilities.

### **Lego Friends:** (Peacock, Prime, Netflix)

Autumn, a spirited nature-lover born with a limb difference, shares her story through adventure, friendship, and fearless play, showing that difference is powerful, and every challenge is worth climbing.



## Podcast



### **Parenting Children with Limb Differences** (Spotify & Apple)

Our heartfelt, practical podcast by parents and for parents raising children with limb differences - where lived experience meets advocacy, community, and everyday joy.

This is just a short list. For an extended collection of options, visit the Resources page on our website.

# Toys & Play: Inclusive Options

Toys, Dolls, and Play can be powerful teachers and tools for inclusion. Many toys don't need any adaptations for your child to enjoy playing with them. Here are some adaptive ideas designed with children with limb differences in mind.



## Hello Mayana

Dolls with limb differences to help educate and normalize disability



## Barbie

Multiple dolls released that feature different visible differences, including prosthetic legs



## A Step Ahead Prosthetics

A custom prosthetic applied to an American Girl Doll

## EazyHold

A secure, adaptable gripping aid that can be applied to various objects.



LEGO



Kikilishop

## Adaptive Scissors

Safe and comfortable cutting. Enables hands-free use by pressing with palm, elbow, forearm



Find more toys and tools listed on our website.

# Supportive Communities & Online Groups

Connection Matters. We believe in communities rooted in kindness, collaboration, and respect for lived experience. The groups listed here reflect diverse approaches to support and advocacy. Your journey is unique, and you deserve spaces that honor it.

Many of these communities offer quality responses and heartfelt support. You may hear a range of perspectives - some affirming, some challenging. We encourage grace, curiosity, and kindness in every exchange. Your voice matters and so does your growth.

## Facebook Groups

Amniotic Band Syndrome (ABS), Limb Difference Collective Foundation, Limb Difference Families, LimbBo Foundation, & More

Organizations supporting the community and providing resources or events include:

- Limb Difference Collective Foundation
- Amputee Coalition
- Beautifully Made Community
- Camp No Limits
- Hands to Love
- Helping Hands Foundation
- Easter Seals
- Jordan Thomas Foundation
- LimbBo Foundation
- Limb Difference Foundation
- Moxie Adaptive
- War Amps
- & more

We know that every family's journey is unique, and experiences with support groups can vary. If one space doesn't feel quite right, there are many others ready to welcome you with open arms.

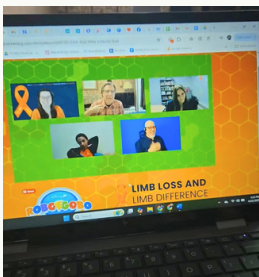
You'll also find individuals sharing their stories on social media - offering insight, encouragement, and connection. Follow those who's story resonates, and feel free to share your own story when you're ready. Whether you're joining an existing community or creating your own, your voice matters.

# Together in Every Way

Snapshots from our limb difference community -  
real families, real joy, real connection



Gathered in strength and celebration



Even miles apart we  
show up to support



Volunteers make it possible



Tools that tell stories



Proud, Playful, Powerful



Innovation meets  
independence



Connect & Inspire

Follow and tag us on social media to see and share your community coming together!

# About the Limb Difference Collective Foundation

## Mission

Empower and support families and individuals with limb differences through community engagement, resources, and advocacy.

## Initiatives

- Community events and meetups
- Educational resources
- “Hugs in a Box” care packages
- Advocacy and awareness campaigns
- Cool merchandise for purchase
- Partnerships with national and local organizations and businesses with inclusive products & services



# Join Our Wolf Pack

Be part of something bigger - join our community of families connected by limb difference.

Membership is free and comes with fun perks:



Monthly Newsletters



Special Offers and Prizes



Holiday Cards, Birthday Shout Outs & More!

Complete the form online: <https://forms.gle/A1kCoeA2cwRXBxEk7>



## Wolf Pack

### MEMBERSHIP CARD

Name:

You don't have to travel this  
journey alone.  
We're here when you're ready.

## Contact us:



630-403-8076



[limbdifferencecollective.org](http://limbdifferencecollective.org)



[info@limbdifferencecollective.org](mailto:info@limbdifferencecollective.org)



Limb Difference Collective



[@limbdifferencecollective](https://www.instagram.com/limbdifferencecollective)



Illinois & beyond



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