



Children Having Infant Limb Deficiency

Offering support to new parents of a child with a limb difference



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Dear New Parents,

Pregnancy is the most amazing time in a woman's life. When the test comes up positive, you know your life is going to change forever. Most women have visualized holding their precious new born for the very first time. You imagine the first cry, you imagine yourself holding your child closely to your heart. You count all ten fingers and toes. Baby is healthy.

Sometimes things don't go to plan and complications develop. Our pages don't intend to diagnose problems, we really hope and recommend you speak to your doctor or midwife first.

We do understand that during this time it's nice to know you aren't alone. So if you have had a bit of a scary time during pregnancy, labour or beyond and need to speak to someone about your child's limb difference, please contact us.

My name is Katherine Moffett. I am the founder of C.H.I.L.D Incorporated. My daughter Sienna was born in July 2008 and she was born with rare limb differences. We found it difficult to get through the first couple of days as we did not know where to find information, had no idea what limb deficiency was and had no known access to a support network. I was not even offered counseling at the hospital she was born at and this is why C.H.I.L.D was established. All I want to do is help new parents. Even if that means a shoulder to cry on or an ear to listen.

Now our support network offers support to families from all over the world via the internet. We also provide support over the phone or face to face. We are based in NSW but have families from all over Australia and throughout the world involved. All of which are willing to talk to you to share their thoughts, offer a shoulder and lend an ear.

Our website is www.childorg.net.au

Good Luck with your beautiful new child and we wish you all the best.

Katherine Moffett

President C.H.I.L.D Inc.



Celebrate Your New Baby!

"I encourage parents to cherish every moment they have with their Newborn as they grow up so fast."

-Katherine Moffett



Congratulations on the birth of your beautiful new baby.

You're probably confused about why your baby was born this way. You have either just found out about your newborn's limb difference or you found out through an ultrasound before birth. Regardless of whether you found out before birth or not, it is still a shock. It is natural to mourn the healthy baby you were expecting. So don't feel like a bad parent if you cry. You're not. You're just human.

You require an adequate explanation from the doctor, counseling and the reassurance that experts are available to give you detailed advice regarding your child's condition.

Remember to let yourself enjoy your child the same way any parent would - by cuddling or playing, watching for developmental milestones (even if they're different from what they would be if your child didn't have a birth difference), and sharing your joy with family members and friends. Your child has no idea that there is a difference and still needs the same amount of love and devotion any newborn craves.



Chances are you may not see your baby much during the first day, this is because there may be tests that need to be conducted on your newborn. Trust that the doctors of this hospital have your and your newborn's best interests at heart. You may be able to be present while ultrasounds, x-rays and other tests are being done. Do ask your partner though to assist the baby through the appointments. You do, after all, need to rest and recover from the birth.

It is understandable that you may want alone time and do not want to contact friends out of a fear that they will think your baby is inadequate. This comes from experience. It is important to have your loving family and your close friends around you to help you through the initial shock. Be sure to ask questions and if the doctors are unaware, ask them to contact the

closest Limb Deficiency Clinic to enquire as to whether someone can come out to see you before you are discharged. If you found out about your newborn's limb differences before birth, you may have already met with your local Limb Deficiency Clinic. Get in contact with the doctors you have been speaking to, this is so that they can organise a counsellor or a representative to come out and examine your baby.

- Take lots of photos! Your newborn will grow up so fast! It is also a good idea to get impressions done of your newborn's hands or feet (which ever is affected) especially if surgery needs to be done in the near future. This is a very beautiful way to preserve your baby's special hands and or feet before surgery changes the appearance. Even if surgery is not required, it is still a very beautiful keepsake.

- Remember to let yourself enjoy your child the same way any parent would - by cuddling or playing, watching for developmental milestones (even if they're different from what they would be if your child didn't have a birth defect), and sharing your joy with family members and friends.

- Many parents of children wonder if they should send birth announcements. This is a personal decision - but remember that the fact your child has a limb deficiency doesn't mean you shouldn't be excited about the new addition to your family. There is nothing to be embarrassed about and friends will not think any less of you or your child because they are a little different than what was expected. Your newborn has no idea that there is a difference and still needs the same amount of love and devotion any newborn craves.

Over the next few days, your emotions are going to go on a wild rollercoaster ride, whether your baby was born with limb differences or not, you and your body has just undergone an immense amount of stress giving birth. Talk about your feelings with your partner and family. Your doctor may be able to arrange for you to meet with a counsellor.

Get used to your newborn. When you bathe her really get a good look at her body to make sure there isn't anything else you would like doctors to look at. It does get better. It is upsetting to begin with but this is your child. This is the baby that you have carried for nine months, the baby that you have been waiting for. Don't put yourself down. You have a special little child that needs your love, especially now.

The hospital will help you. The nurses and midwives are there to help. Your family and friends will play a very big role during those first few days and are there to listen.

Unless there are any other medical problems other than the limb difference, your newborn, after being monitored and checked will be left in your care and discharged from the NICU. Congratulate yourself! You have a beautiful new baby and we cannot reiterate that enough. So cuddle up, give breastfeeding a go and enjoy all of your newborns firsts.

If you need any advice, have just found out your newborn has a limb difference or just need to chat, please email me at: kate@childorg.net.au or visit us at www.childorg.net.au



Fathers Grieve Too



Most of the time, fathers are neglected grievers. While we know a lot about grief now, people still aren't sure how to respond to a man's feelings. It's safer to ask how your wife is doing than to ask how you feel. And as a man, you have a lot of thoughts and feelings now.

You may feel: angry, depressed, lonely, hopeless, disappointed, confused, hurt, sad, afraid, out of control, confused, empty, guilty, helpless, like a failure, frustrated. Or on the other hand, you could feel calm.

You may have times of real panic and worry about your family. You may have lost the confidence of being the Daddy who makes things right. And you may spend a lot of time asking yourself "Why was MY child

born this way?" This can be one of the toughest times in your life, and it's important to take care of yourself and the hurt you're feeling.

You may find you need to be strong and take control. You may feel like you're talking care of everyone else, attending the appointments with your new baby, consoling your wife. You never really "get over" the pain of when you found out about your



newborns disability but as you begin trying to get back to normal you may find your feelings popping up when you least expect them. Along with some feelings mentioned earlier:

You may feel distant from people. And you may find yourself angry. As mentioned before, it is extremely important to remember that your newborn needs you. Your new child needs his father's love as much as a child that has been born with no problems.

Talking

One of the things that can help your hurt is talking about your child to family, friends and even your partner. When you don't talk about your child or your experiences and feelings your family may think you're cold and don't care. You may seem distant from each other and out of touch. If you have trouble talking, you may want to do just a little each day with your partner or friends or both. Sometimes even talking to your newborn helps. Remember: Talking may lighten your pain, clear your anger and affirm your feelings.

Working

This may be a time when you want to be careful about your work. You may find yourself using your job as way to cover up your feelings. Work can be a distraction and it can be a relief, but it is seldom a total solution to sadness. It can also be very frustrating. Your partner and newborn need you around. She needs your support.

Marriage

A lot of people think a newborns birth brings couples closer. This does not always happen necessarily. You may both be so wiped out with your feelings that you can't lean on each other. You may be scared about what's happening to each other and to your relationship. If that happens remember: It's important to keep talking to and not block your partner out because of guilt or hurt...even now. Talk about how you met. Remember how you fell in love. Share what you like about each other. Go out on a date, even if it's a short walk. Touch and hold each other. Realise you both need to approach this situation your own way - respect each other's way of approaching the baby and her difference.

If you want more information, the websites below may be able to offer some assistance.

C.H.I.L.D Incorporated: - www.childorg.net.au

Amniotic Banding Syndrome - <http://www.amnioticbandsyndrome.com/index.php>

Aussie Hands - www.aussiehands.org.au

Reach UK - <http://www.reach.org.uk/ReachCMS/>



Able Minibuses & Limousines - Your Transport Specialists
www.ableminibuses.com.au - 02 9738 8388





Siblings

The birth of a newborn with any sort of disability can really confuse any siblings. The child may not understand why the baby is different to other babies. Hopefully, the information below will help you talk to your child about your newborn's differences.

Finding the right words to explain a child's difference to another child can be extremely difficult. Depending on the sibling's age and their stage of development, consider their capacity to understand the issues and their ability to express themselves.

Having good open communication can contribute significantly to a sibling's wellbeing. They need to know that you are able to answer any questions they may have about their new baby's difference. They may also benefit from talking to someone outside of your immediate family.

The youngest child may not even notice their new baby's difference unless it's plainly obvious. By the age of four though, children will definitely notice if someone looks like everyone else, and they often start blurting out questions. They might even wonder if a disability can happen to them. How you respond to those first innocent and curious observations will affect the way your child thinks about disabilities and treats others as she grows up.

How to talk to your Children / Teen about the new baby's difference

If your children go to primary or high school and often have friends over, help them work out how to explain the difference to their friends.

Depending on the sibling's age, explain how the disability was caused, because children may worry about it happening to them, or feel they caused the problem in some way. Reassure that this was not their fault and that the baby is just special. But make sure you explain that everyone is special in their own way.

Children when they are under the age of five or so, are very accepting; they don't usually notice differences and only usually asked once. You do though need to give your other children permission to ask questions openly and give them answers so they understand what is happening.

Listen to children's feelings. Think about what you say sometimes in the presence of young children. Do not speak about any surgery in front of your children as sometimes it scares them. If surgery is required on the newborn though, make sure you explain to your child as simply as you can that the baby needs an operation to make him/her feel better. Encourage siblings to be proud of their baby's achievements and to realise the difficulties she may have had in getting there.

So following these steps may help:

Look out for an opening

The first time your child notices that their baby has a difference; take the opportunity to strike up a conversation about differences. Explain that there are actually lots of ways that people are different, such as hair colour and skin colour and physical appearances. The aim is to promote an attitude of acceptance and inclusion.





Answer questions directly

As always with young children; don't go into a long-winded response. If your preschooler asks why your new baby is missing half of their arm, keep the answer short and do not get into a long-winded discussion. A teen on the other hand, you can sit down and explain what you know, the problem is genetic and so on.

For the littlies, you can either use the "That's just how God made her" approach or "When baby was in mummy's tummy, she just grew a little differently. But she will be okay and will be able to do all the things you can do like play, sing, and dance."

Watch what you say

Take care in how you describe people with disabilities. Avoid outdated, derogatory terms. Try to put the emphasis on the person and not the disability. Say "your sister has no arm" rather than "the baby has a

disability". Also try to avoid referring to non-disabled children as "normal", as it implies abnormality in others.

When you and your child encounter someone outside your home with a disability, there's no need to say "don't stare" or hurry her along. Your preschooler might get the impression that she can't ask you questions.

Emphasis what's the same

Your child may be physically disabled but she's still a child. Talk about the things that they have in common. For example: Sienna has brown eyes just like you! And she loves eating spaghetti just like you.

Offer reassurance

Sometimes children worry that a limb difference will "rub off" on them or is "catching". Let your children know that it doesn't work that way, it is not something they can catch.

Teach respect

If you hear your child referring to someone with a difference or disability as "stupid" or saying that he walks or talks "funny", take a moment to discourage such teasing. Explain how much those words can hurt and really make it clear that looking or behaving differently doesn't make someone inferior.



If you feel that you are depressed, please visit www.beyondblue.org.au and your local doctor.

Your New Grandchild

Every grandparent hopes and prays that a new grandchild will be healthy. We count our grandson's fingers and toes after he is born. We keep an eye on our granddaughter to make sure she is developing "normally."

Most of the time, we breathe a deep sigh of relief because our grandchild is just fine. But sometimes there are challenges. We may find out that the newest addition to our family has a disability. This news can be very hard to hear. We feel shocked and sad. We are angry. We find it hard to understand how this could have happened to our family. We ache for our grandchild—and for the child's parents.

These feelings are painful. As grandparents, you need to take time to grieve the loss we are feeling. And then we need to get busy. That's because we have many special gifts to offer our families right now. They need us more than ever.

Tips for Dealing with Disabilities

You may be helping the child's parents cope with the child's special needs or you may be raising your grandchild yourself. In either case, you can't take away the pain that you or your grandchild's parents are feeling right now. You can't change

what has happened to your grandchild. But you can offer your support to the child and to the rest of the family.

Show your grandchild every day that you love him for the special person he is; Listen when the child's parents need to talk; Support the decisions they are making, even if you don't agree with all of them; Show that you are interested in the special programs and therapies they have found for the child; Offer to help with household chores.

You can also do a few things to help yourself cope with your grandchild's disability. Even if you are not raising the child, it's important to stay as involved as you can in the child's life. This will help you become more comfortable with his or her condition. Talk to other grandparents who have grandchildren with disabilities. Join a support group for families of children with disabilities, C.H.I.L.D can offer you support online via our website and through facebook. We also offer over the phone and face to face support. We do also have a large database of parents and grandparents you can contact who have been through what you are going through. You will feel better when you can share your feelings with people who know what you're going through. You can learn more about limb deficiency. And, you may pick up some tips on how to support your family. You might even encourage the grandchild's parents to join a support group too.

Learning about Limb Deficiency

Learn as much as you can about your grandchild's condition. This will help you cope with what is happening. A number of conditions can affect young children. Each has its own causes and treatments. Some of the more common limb conditions are:

Cleft hand and cleft foot - These are very rare conditions where the separation between the third and fourth fingers or toes extends deep into the hand or foot. Plastic surgery may be needed to help correct this abnormality.

Club foot - This is an abnormality where the front part of the foot turns toward the inside of the heel. Club foot is treated by gentle stretching to reshape the position of the foot. The foot is stretched and then placed in a cast for a few weeks. The cast is removed, the foot stretched a bit further, and the cast is put in place for another few weeks. This process continues over a long period. In some cases, surgery is needed.



In Uterus Surgery - has been performed to free limbs from amniotic bands that threaten to amputate limbs. Results of the first surgeries of this type were published in the "Journal of Ultrasound in Obstetrics & Gynecology." It is the first minimally invasive treatment to correct a non-lethal fetal condition. The first fetal surgery recorded for ABS was in 1997.

With Amniotic Banding no two cases are exactly alike. There are several features that are relatively consistent: syndactyly (webbed digits), distal ring constrictions, deformity of the nails, stunted growth of the small bones in the digits, limb length discrepancy, distal lymphedema (swelling), and congenital band indentations.

Congenital hip dislocation - This is when the hip bone and thigh bone are underdeveloped, which leads to dislocation of the hip. Treatment involves holding the hips in place so that they can continue to develop properly. This can be accomplished through the use of splints, harnesses, and sometimes surgery.

Pollicization - Pollicization is the surgical creation of a thumb from a finger, usually the index finger. There are several techniques, but they have in common steps to shorten, rotate, and reposition muscles to achieve a functional and aesthetic result.

Polydactyly - This is the presence of extra fingers or toes. This condition can be corrected with surgery to remove the extra finger or toe.

Syndactyly - This is fusion of one or more fingers or toes. Surgery is useful to separate the fingers or toes, and to add skin to the places where it is needed.

Amniotic Banding Syndrome - Not all limb differences are caused by genetics. Amniotic Band Syndrome is a set of congenital birth deficiencies believed to be caused by entrapment of fetal parts (usually a limb or digits) in fibrous amniotic bands while in uterus. In other words: Before the baby was born the body parts that shows signs of ABS (arm, fingers, toes, etc.,) were caught up and entangled in string-like bands. This caused abnormalities that were present at birth. Amniotic Band Syndrome is not genetic (i.e. not inherited).



ROTARY CLUB OF PROSPECT (NSW) INC
DISTRICT 9690
Chartered; 19th May 1994
Incorporated; 20th June 1995



C.H.I.L.D is proudly associated with The Rotary Club of Prospect. The Rotary Club of Prospect (NSW) Inc is comprised of a group of professional and business people with the skills and expertise in a broad range of disciplines, who are prepared to offer their services to improve the quality of life in our community. Rotary Health has undertaken a research grant from monies C.H.I.L.D has raised to research genetic limb deficiency in newborn babies.

The Rotarians of Prospect assist us in our fundraising efforts. If you interested in more information, their weekly meetings are held every Wednesday morning, 7:00am for a 7:15am start. Meeting Venue - Max Webber Centre, Blacktown Library, level 1, Flushcombe Road and Alpha Street Blacktown. Parking in basement, entrance of Alpha Street.. Take lift to first floor.

For more information, please contact Mr Bruce London on 0408269200



What are Congenital Limb Differences?

Congenital limb differences occur when a portion or the entire upper or lower limb fails to form normally when the baby is developing in the uterus.

What causes Congenital Limb Differences?

The cause of congenital limb differences is unknown. However, risk factors that may increase the likelihood of a congenital limb defect include the following:

- conditions affecting the baby in the uterus during development
- exposures by the mother to chemicals or viruses while pregnant
- specific medications
- How are Congenital Limb Differences diagnosed?
- The diagnosis of congenital limb differences is made at birth. The most common congenital limb differences can be classified as follows:
- complete absence of the limb
- failure of the portion of the limb to separate (commonly seen in fingers or toes)
- duplication (commonly seen as extra fingers or toes)
- overgrowth, the limb is much larger than the normal limb
- undergrowth, the limb is much smaller than the normal limb
- congenital constriction band syndrome - early rupture of the amnion (inner membranes that cover the fetus in the uterus and contains the amniotic fluid) resulting in bands that may become entangled in the extremities of the fetus, causing immobilization, constrictions of the limbs, amputations, and other deformities.

C.H.I.L.D understand that the words "limb defect" and "disabled" may be hard to associate with your precious new baby. You will find in a lot of the websites you research and information you read, the words difference and deficiency are used in place of the other words.

It is hard to come to terms with your newborn being born different. She will adapt. She will learn to do things in her own special way. Prosthetics may be offered at a later date as your child grows.

If you wish to speak to one of our wonderful volunteers who can offer you an ear, please contact kate@childorg.net.au

- Congenital limb differences may also be associated with other bone conditions or syndromes. Always consult your child's physician for a diagnosis

Treatment for Congenital Limb Differences:

Specific treatment for congenital limb differences will be determined by your child's physician based on:

- your child's age, overall health, and medical history
- the extent of the condition
- the type of condition
- your child's tolerance for specific medications, procedures, or therapies
- expectations for the course of the condition
- your opinion or preference

The overall goal for treatment of congenital limb deficiency is to provide the child with a limb that has proper function and appearance. Treatment goals can vary for each child. Some goals may include the following:

- promoting normal development
- discovering sense of independence
- encouraging self-care
- improving cosmetic appearance
- adaptation

There are no standardized treatment protocols for congenital limb deficiency. Treatment options may include:

- prosthetics (artificial limbs)
- orthotics (splints or braces)
- surgery
- rehabilitation (physical or occupational therapy)

*Reference:

<http://www.chp.edu/CHP/P02752>



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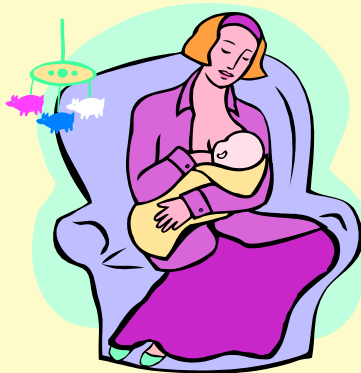
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“Breast is Best! Give it a go!”

Disclaimer: Information provided in this booklet for is for informational purposes only; it is not intended as a substitute for advice from your child’s medical team. The information in this booklet is not to be used for diagnosing or treating any health concerns you may have or diagnosing your Childs limb deficiency- Please contact your physician or health care professional for all your medical needs. We are a support network for families. This booklet is copyright to C.H.I.L.D Incorporated. This booklet was paid for by the volunteers of C.H.I.L.D Incorporated.