

My baby has a...

Cleft Lip/Cleft Palate

You and your baby are not alone. Each year, about 89 babies in Kentucky and about 7,088 babies in the United States are born with a cleft lip and/or a cleft palate.

What is cleft lip/cleft palate?

A **cleft lip** forms when the skin that makes up your baby's lip does not join together properly during pregnancy. A **cleft palate** forms when the tissue that usually creates the roof of your baby's mouth does not join together properly during pregnancy. Your baby may have a cleft lip, a cleft palate, or both.

How did this happen?

Cleft lip or cleft palate can happen to anyone. Mothers who have diabetes, who smoke, or who are white are at a higher risk of having a baby with a cleft lip, cleft palate, or both. However, your baby's birth defect is **not** your fault. There is no known way to prevent cleft lip or cleft palate. For future pregnancies, doctors recommend having a healthy weight, eating well, taking prenatal vitamins, and not smoking or drinking, to have the best chance of a healthy pregnancy and baby.

What's next for my baby?

Your doctor will most likely repair your baby's cleft lip when they are between 10 weeks and one year old. Cleft palate repairs usually happen later, when your child is between 6 months and 18 months old. Sometimes, children will need additional surgeries to repair their lip or palate, even when they are teenagers. Ask your doctor about their treatment plan for your baby.

How can I help my baby?

Children born with cleft lip or palate often have problems with feeding, speech, ear infections, hearing loss, and problems with their teeth. Keep a close eye on your baby, and go to your doctor if you have any concerns about his or her development. With love and support from their families, children born with cleft lip or cleft palate can enjoy active and normal childhoods.



Daniel and Jacob's Story—Written by their mom, Kristin

I have a vivid memory of hearing the doctor say to me, "Your son will have a cleft lip and palate." Time stopped temporarily, and I felt suspended on the exam table. Cleft lip and palate? Me? My baby? As we anxiously awaited the birth of this special son, I played over the scenarios in my mind. Would he eat like other babies, would he look too very different? The wait was agony. When the baby came he looked up at me with his steel blue eyes and cherubic cheeks. Then, he nuzzled me softly, and I knew we would be alright. I would buoy him up and help him thrive, and he would do the same for me. Three years later, it was like a bad movie stuck in replay, "Your son will be born with a cleft lip and palate." Wait a minute, I thought, I have already done this. I already paid my medical bills; we completed the surgeries. We have to do this again? Six months later my third son was born like his older brother, with a cleft lip and palate. This baby would suffer more with a more complicated condition. But it didn't matter, I knew how to do it now, and any difficulties we experienced were swallowed up in our family's love. Both children are resilient and active. My boys are strong and healthy. We have endured much and are grateful and stronger for it.

To read more stories about families like yours, go to: <https://www.cdc.gov/ncbddd/birthdefects/stories/cleftlip.html>

Available Resources

The Commission for Children with Special Health Care Needs has a mission to enhance the quality of life for Kentucky's children with special health care needs through quality service, leadership, advocacy, education and collaboration. Eleven offices and seven satellite clinic locations serve children across the state. Commission staff work with families to help them get the care their children need. Nurse care coordinators assist families with medical needs and Family to Family mentors are able to guide families seeking answers to educational, social, and emotional concerns. <http://chfs.ky.gov/ccshcn/>

The American Cleft Palate-Craniofacial Association (ACPA) is a non-profit association of interested individuals and health care professionals who treat and/or perform research on oral cleft and craniofacial conditions. ACPA is unique – it is a multidisciplinary organization of over 2,500 members, representing more than 30 disciplines in 60 countries. <http://acpa-cpf.org/>

SMILES is a group of dedicated families who have developed a first-hand understanding of the needs of children with cleft lip, cleft palate, and craniofacial deformities. Through our personal sensitivity, energy, knowledge, and love we are dedicated to improve the lives of these children in our country and around the world. <http://www.cleft.org/>

Additional Information

The Kentucky Birth Surveillance Registry (KBSR) is dedicated to preventing birth defects through ensuring timely, complete, and accurate birth defects surveillance; referring children with birth defects to appropriate services; providing data for research studies after appropriate review; and implementing birth defects prevention programs in Kentucky. You can contact Kentucky's Birth Surveillance Registry at kbsr@ky.gov.

For more information about cleft lip/cleft palate, visit:
<https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html>

Information adapted from: <https://www.cdc.gov/ncbddd/birthdefects/types.html>

