RESEARCH AND RECENT STUDIES
Cleft Birth Defects and Health Insurance

Families of children with craniofacial and cleft disorders often have issues with their health insurance companies to get the necessary services and surgeries needed especially when dealing with HMOs. Suggested words to use are: My child has breathing problems. My child has difficulty swallowing. My child has difficulty biting. My child cannot chew like other children. You may also try using the medical terms for these problems. CleftSmile.org cannot guarantee that this will help as these are suggestions. You must try to convey to whoever will approve the treatment that normal everyday functions which others do automatically is painful or nearly impossible for your child who suffers from a craniofacial condition or cleft birth defect. Emphasize that the requested procedures will help restore correct function to the affected area of the body. Do not emphasize that it will improve his or her self esteem. Focus on the bodily function.

If the HMO denies treatment based on dental, ask for a plastic surgeon to review your case.

What’s the very first thing I should do?
Read your healthcare insurance policy including the fine print. If you don’t have it, ask the human resources or benefits personnel to provide you with a copy and familiarize with its contents. If you have questions, don’t hesitate to ask.

Do words matter? What words are recommended? What words should I avoid?
Yes. Words do matter. Do not use words like self esteem, cosmetic, reconstructive, and dental. These words or conditions are considered cosmetic or elective.
What else do I need to know to advocate for my child’s cleft birth defect?

You must be persistent. Always document your experience, your phone calls, and your emails. Make copies and keep a file. Keep records of denied procedures.

Have photos on hand or ask your doctor’s office to provide photos to case care workers so they can readily view your child’s condition.

Fight for one procedure at a time. Try to demonstrate to the insurance company that paying for one procedure now may eliminate the need for future procedures, thus saving the company money in the long run.

Find out if your state already has laws on the books requiring insurance companies to cover patients with cleft birth defects and/or craniofacial conditions. If you don’t know where to check, ask us at CleftSmile.org.

What if my healthcare provider denies coverage for my child’s treatment?

Sadly, this is becoming more widespread—especially with HMOs—denying coverage for treatment. The person who denies the claim is usually an administrative person without any medical background. So before talking to anyone, be persistent and ask to talk to a case care manager or someone who has knowledge about cleft birth defects.

Do I have any rights if I’m denied?

You have the right to ask for medical care that your child needs. That said you may need to go to an appeals process which requires numerous steps and the third party may be paid by the insurance company. Your state may also have laws that protect you. Check your state insurance commission, your elected officials, contact us at CleftSmile.org, or ask Rachel for assistance.

Should others get involved?

Possibly, find out if there are existing craniofacial/cleft palate teams already working in place in your state. Find out if state medical associations are involved in this advocacy or would they like to start organizing. Find a cleft palate parent support group to network with; there is greater power in numbers.

Ask elected politicians to support state and federal legislation protecting patients with special healthcare needs.

What’s the last straw?

Think about who can wield power of your insurance company. Again be persistent and creative. Contact elected officials, the media, and the state insurance commission. Consider consulting a lawyer if you feel your child’s rights as a patient are violated.
Why do I have to fight this hard?
You're right. It does not seem fair. It’s not fair. Do you want more information about dealing with the health insurance companies? Do you want to connect with other families of children with cleft palate birth defects to find out what they have done and are doing in regard to coping with and conquering insurance issues? Please contact Rachel Mancuso for assistance.

Do you have more questions?
For questions and resources about cleft lip and cleft palate, please contact: The Cleft Lip and Palate Foundation of Smiles. Cleft lip or palate is one of the most common birth defects, currently affecting one in 600 children in the United States. The Foundation was formed by a young mother of twins both born with cleft lip and palate. The Foundation offers positive support to parents of children with craniofacial differences by offering news, information on cleft palate teams, state by state resources, birth registry listings, and a online community where you can register to meet other families in your local area who are going through the same or similar concerns and where you can share and express useful information.

References
American Cleft Palate-Craniofacial Association
Dealing with your insurance company or HMO
Shriners Hospitals for Children
States which have mandated care for cleft palate birth defects
National Association of Insurance Commissioners:
state by state map

Other Research from The Cleft Lip & Palate Foundation of Smiles
Research and Recent Studies:
- Causes of Cleft Lip and Palate: Birth Defects
- Causes of Cleft Lip and Palate: Clomid
- Causes of Cleft Lip and Palate: Hydrocodone
- Causes of Cleft Lip and Palate: Special Education
- Causes of Cleft Lip and Palate: SSRIs
- Causes of Cleft Lip and Palate: Topamax