



American Cleft Palate– Craniofacial Association

1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514 USA

TEL 919.933.9044
FAX 919.933.9604

www.acpa-cpf.org
info@acpa-cpf.org

Dealing with your Insurance Company/HMO

What do I do if my insurance carrier/HMO denies coverage for necessary treatment?

Unfortunately, this situation is very common across the country, particularly under managed care. In many cases, the person making the initial denial does not have a medical background, so be sure you are dealing with a case manager or someone else who is knowledgeable about the condition. Keep track of every time you contact the company, noting the person you talked to, the date and time, and a summary of the conversation. Try to find one sympathetic person. Some policies contain a clause about “genetic birth defects” that requires coverage for any medical treatment that is a direct result of a birth defect. (This may not be contained in the policy summary booklet, so ask a representative of the company to look it up.) Be polite, but assertive.

What rights do I have?

As a paying customer of the company, you have a right to ask for the medical care you need. If your initial request for treatment is denied, you may want to investigate the appeals process. Most companies have a series of steps you must go through. (Keep in mind that the “third party reviewer” of your case is probably paid by the insurance company.) Your state may also have laws to protect you. Check with your state insurance commission, state representatives or legislature, or the American Cleft Palate-Craniofacial Association. The National Association of Insurance Commissioners can be found on the web at www.naic.org.

What if my insurance carrier/HMO calls these procedures “cosmetic”?

Adults may have a particularly difficult time winning an appeal on this issue. Again, be sure you are dealing with a person with a medical background at the insurance company (such as a case manager), and have your primary care provider write a letter on your behalf stating the medical benefits of the treatment. Emphasize that the requested procedures will help restore correct function to the affected area of the body, not just influence self-esteem. Provide pictures if

necessary. You may request information about cleft and craniofacial conditions from the American Cleft Palate-Craniofacial Association at 1-800-24-CLEFT or www.acpa-cpf.org to help educate your insurance company on necessary treatment for individuals born with cleft or craniofacial birth defects.

What if my insurance carrier/HMO calls these procedures “dental”?

Try to have your case reviewed by a plastic surgeon. Obtain letters of support from your surgeon, team, and primary care physician, stating the *medical* need for these procedures. In fact, letters from the dentist or orthodontist may not be the most helpful to your case. Using descriptive terms like “presurgical maxillary orthopedics” to describe orthodontic palatal expansion may keep the procedure from sounding “dental.” Fight for one procedure at a time. In all instances, it may help 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. Be aware that medical insurers sometimes classify the dental and speech problems associated with cleft or craniofacial birth defects as “secondary conditions.” It is important to demonstrate that these treatment needs are a direct result of the initial condition and that they are not just consequences of earlier surgeries. Emphasize that these procedures are necessary to ensure the best possible outcome for the patient.

What if my insurance carrier/HMO calls this condition “pre-existing”?

The purpose of the pre-existing condition clause is to prevent people from signing up for health insurance right before treatment is needed for a medical condition they have had for a long time. Do not allow your insurance policies to lapse, because it puts you at risk for this type of denial. If an insurance company you want to use refuses to take you as a client, ask if the company has a period of “open enrollment” during which you can sign up for coverage. Be aware that there may

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be a waiting period before medical treatment will be covered for a pre-existing condition. Insurance regulations differ from one state to the next, so check with your cleft palate team or your state's insurance commission about laws governing pre-existing conditions in your state.

What if my insurance carrier/HMO will not allow me to see a team?

It may be helpful to emphasize to your insurance company that team care may save money in the long run. For example, several procedures provided by different medical specialists may be combined into one surgery, thus saving on hospital bills. Find out if your team and/or doctor is a member of the American Cleft Palate-Craniofacial Association, and explain to the insurance company that membership implies a dedication to knowing the most current developments in the field of cleft and craniofacial care. For information about the importance of a cleft palate/ craniofacial team, contact the American Cleft Palate-Craniofacial Association at 1-800-24-CLEFT or www.acpa-cpf.org.

What if all else fails?

Seek help from the human resources department that represents your employer. The employer has made a decision to use this insurance carrier, and they need to know if employees are dissatisfied. Think about who else may hold influence over the insurance company. Families have been successful in winning their cases by involving their elected officials, the media, and the state insurance commission. You may also want to consult a lawyer if you feel that the patient's rights are being violated.

Are there sources of financial aid available if I cannot win my appeal?

There *are* other sources of medical coverage for patients with cleft and craniofacial conditions, though most of them are offered through state and federal programs which generally have maximum income requirements. Programs for "Children with Special Health Care Needs" (DSCC), federally funded through the Maternal and Child Health Bureau under Title V and available in most states, may support this treatment. (The extent of services varies from state to state. Check the "State Links" section of www.mchdata.net, or contact your state Department of Health.) You may also want to ask your Department of Health about other state and federal programs for which you might qualify, such as the Children's Health Insurance Program, or CHIP. (Information about CHIP is also available at www.insurekidsnow.gov or 1-877-KIDS-NOW.) Adults may be able to

receive services through their state Office of Vocational Rehabilitation.

Selected Shriners' Hospitals for Children also provide cleft and craniofacial services. For information about their 22 hospitals in North America, or to obtain an application for services, call toll-free 888-385-0161. In addition, some organizations that send teams of doctors to foreign countries to perform cleft repair surgeries may have services available in the United States as well. Keep in mind that you most likely will not be able to select your own surgeon.

There are currently no national nonprofit organizations that offer financial assistance specifically for medical care of patients with cleft and craniofacial birth defects. (There are resources for *non-medical* expenses, such as when the patient must travel to a treatment facility.) Talk to your doctor or team about what state or local programs may be available to you. You may also want to check with your local chapters of Easter Seals, March of Dimes, or other local charitable organizations for emergency grants.

How do I choose the best insurance carrier/HMO when I have a family member with a special health care need?

Family Voices and Families USA (see below) both provide excellent written materials on this issue. You may contact them directly for copies of their publications.

What can I do to advocate on behalf of children with special needs?

The organizations on the resource list below can provide you with suggestions about how to advocate for these children. The key is to be creative and persistent. Document your experience with your insurer, and keep records of denied procedures. Ask your elected representatives to support state and federal legislation protecting patients with special health care needs. Some states already have laws requiring insurance companies to cover patients with cleft and/or craniofacial conditions; you can check with the American Cleft Palate-Craniofacial Association for more information. See if the cleft palate/craniofacial treatment teams in your state already work together as a coalition to help fight these issues, or whether they would be willing to organize one. State medical associations may also be involved in advocacy. Ask your health care providers to help you identify state and national associations to contact.

Please contact ACPA Family Services for further information or for a referral to a cleft palate/craniofacial team.

Other Resources:

Listing does not imply endorsement, and the American Cleft Palate-Craniofacial Association is not liable for the information presented by other organizations.

Genetic Alliance

800-336-GENE, www.geneticalliance.org

The Genetic Alliance is a national coalition advocating for the common concerns of patients and families living with genetic conditions. Ask about their *Health Insurance Resource Guide*.

Families USA

202-628-3030, www.familiesusa.org

Families USA is a national nonprofit, nonpartisan organization working for high quality, affordable health care for all Americans. The website includes information on federal managed care legislation, a state-by-state guide to managed care issues, and valuable links.

Family Voices

888-835-5669, www.familyvoices.org

Family Voices is a national grassroots organization of families and professionals who care for children with special health care needs. The website describes the Children's Health Insurance Program (CHIP), managed care, SSI benefits, Medicaid, and a list of activities in each state.

National Organization of Rare Disorders

800-999-6673, www.rarediseases.org

NORD is an information clearinghouse for those dealing with rare disorders. NORD also offers a drug assistance program, which provides financial aid for certain prescription medications.

Patient Advocate Foundation

800-532-5274, www.patientadvocate.org

This organization's mission is to educate patients about managed care, public policy issues that may affect coverage, and how to clarify the terms of an insurance policy. The organization also provides legal intervention services. The website presents information in English and Spanish.

Cleft Advocate

www.cleftadvocate.com

This parent-run website offers advice and sample letters for fighting cleft-specific insurance denials. General educational resources are also available.

SNAP Medical Insurance Empowerment Program

888-310-9889, www.snapinfo.org

Advisors work individually with parents to creatively determine how to approach their insurance companies for authorizations or reimbursements regarding medical care for children with special health care needs. Families must have private insurance (not Medicaid), and fees are charged on a sliding scale basis.