

## Paying for Treatment of Newborns with Cleft Lip and/or Cleft Palate

### Where do we start?

Paying for a family member's health treatment can be complicated. Health care funding varies from state to state and from one insurance policy to another. It changes constantly.

This factsheet explains who pays for cleft and craniofacial care. It describes problems that may come up with paying for certain services and how to solve them. It also lists service organizations and other resources that can help families pay for care.



### Who pays for cleft care?

Funding for cleft and craniofacial care may come from one source or from a combination of sources, such as:

- Employer-based or group-based health insurance
- Military health insurance (Tricare)
- Health coverage funded by Medicaid
- Health coverage funded by programs like CHIP and CSHCN
- Assistance programs through hospitals
- Assistance from private service organizations

### Does insurance cover cleft care?

Federal law requires that health insurance companies cover (pay for) basic health needs. State governments also have requirements. Each state has a health insurance commissioner who decides which services must be covered by insurance programs in that state.

Most states currently require that employer or group-based insurance policies cover services for cleft and craniofacial care. Tricare military insurance usually covers most cleft services. Unlike group-based insurance coverage, Tricare coverage is regulated at the federal level. So there may be some differences between Tricare coverage and the coverage by other insurance programs in your state.

Families with another kind of policy, like one purchased through a state exchange, may not be covered for cleft care, or may have to follow an approval or appeals process (a special procedure to request payment) for each stage of care.

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If your insurance policy covers cleft and craniofacial care, it may still require you to pay a copay (a fee to cover part of the cost) for each service. To find out more specific information about copays, speak with the coordinator on your cleft or craniofacial team.

### Do we need preauthorization?

Tricare military insurance and many employer or group-based insurance policies require that families get preauthorization for cleft and craniofacial services. This means that the insurance company decides to pay for services on a case-by-case basis. To approve a case, the insurance company usually asks for certain information from a child's doctor.

Families may need to get new preauthorizations from time to time during treatment. When a new stage of care begins, for example, the insurance company may require a new preauthorization even though it has covered a child's care for many years. This is a common challenge for families who are preparing for bone grafting and orthodontics.

Many insurance companies cover some aspects of treatment but not others. An insurance company may also change its policies over time. It is important to check your coverage every time your child has a procedure or a hospitalization.

### What is Medicaid?

Medicaid is an assistance program run by the federal government and state governments. It covers costs of medical care for some people with low income. Medicaid usually covers physician services, hospital services, laboratory procedures, and X-rays.

Families must apply for Medicaid. Each state has a program. After families receive a Medicaid card, they can receive health services. To learn how to apply in your state, go to the website [www.medicaid.gov](http://www.medicaid.gov).

### Does Medicaid cover cleft care?

Medicaid usually covers the major services of cleft and craniofacial care such as evaluations and major required surgeries. Coverage for some aspects of cleft care may differ slightly from state to state. Speech and hearing services, for example, may or may not be covered. To learn more about cleft services covered by Medicaid, ask the coordinator on your child's team.

### What other programs help pay for cleft care?

The Children's Health Insurance Program (CHIP) is an assistance program for children. It provides health coverage for children in families that do not qualify for Medicaid but can't afford other insurance coverage.

Children with Special Healthcare Needs (CSHCN) is a health assistance program for children in families who have applied for Medicaid and CHIP. It is a payer of last resort. This means that it covers medical services only when other insurance or

assistance programs will not.

### Is orthodontic care covered by insurance?

Many children born with cleft lip/palate need orthodontic care, like braces. This type of care should always be filed as a medical claim, not a dental claim.

A health insurance company may deny a claim at first because the service appears to be dental rather than medical. If a claim is denied, a family needs to file an appeal (a second request for payment.) When used as part of a craniofacial treatment plan, orthodontic care is medically necessary.

Obtaining coverage for orthodontic care can be quite difficult. The coordinator on your cleft palate or craniofacial team should be able to help you navigate this challenge.

### Who pays for speech therapy?

Medical insurance usually covers speech therapy for people born with cleft and craniofacial differences (speech therapy can also be obtained through state-run programs; see below). Sometimes, an insurance company denies a claim or limits the therapy to only a few sessions. The company may say that speech therapy is "not medically necessary."

In cases like these, families can file an appeal. The appeal needs to include a statement that says something like, "Speech conditions caused by craniofacial differences are medically necessary and will require X number of sessions due to the severity of the speech disorder." The speech-language pathologist on the team can help.



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### What is Early Intervention?

Every state in the U.S. offers Early Intervention programs, also called EI or Early Intervention Birth to Three.

EI programs are free. They include speech therapy and other services (like physical therapy and occupational therapy) to infants and toddlers between the ages of zero and three. The program usually begins with an evaluation to find out whether a child needs therapy.

### What is an IEP?

Starting at age three, children can get speech therapy through the public school system. This is called an Individualized Education Program, or IEP. This program is free. It starts at age three and continues through high school.

### How do we get an IEP?

To learn about getting an IEP, start by contacting your school district. Sometimes, after evaluating a child, a school decides that his or her speech, language, or motor needs are not severe enough to qualify for services. The school may say that the problem is not “educationally significant.”

This decision does not always mean that a child does not need therapy. Speak with the speech-language pathologist (SLP) on your craniofacial team. The SLP may explain to the school why speech therapy is needed, sometimes at a younger age than usual and sometimes for longer than usual. The SLP can also

help you find other options for speech therapy, if necessary. Can my cleft team help with insurance questions?

Yes. The specialists on a team are experts in cleft or craniofacial care, but they also have experience with issues related to paying for treatment. If an insurance company denies a claim for a service, the team will know the best ways to show “medical necessity.” Your treatment team is a critical resource for the challenges of insurance coverage.

### Do hospitals offer assistance?

Many hospitals across the U.S. offer financial assistance for care. In 1946, the federal government passed the Hospital Survey and Construction Act, also called the Hill-Burton Act. This legislation funds the construction of hospital facilities. It also requires that participating hospitals provide some free care to patients who can't pay.

The hospitals that offer free care are usually public hospitals (run on government funds) or hospitals linked with a state university. The website for your hospital may provide information on financial assistance. Try the following search terms: financial assistance, financial counseling, charity care, indigent care, and payment plan. The coordinator on your cleft team may know about opportunities for this type of aid, as well. He or she may be able to direct you to a hospital office or professional who can help.



### Service Organizations

#### Local Service Organizations

Local organizations such as Lions, Sertoma, Kiwanis, the Scottish Rite Foundation, and Civitan sometimes offer financial aid for emergencies or one-time needs. Local churches and church groups, the Knights of Columbus, and others, may also be good resources.

#### National Service Organizations

The National Craniofacial Association (FACES)

[www.faces-cranio.org](http://www.faces-cranio.org)

1-800-332-2373 or 432-266-1632

FACES provides financial assistance to families of individuals who are receiving craniofacial treatment. These funds go toward support services like transportation, food, and lodging. FACES is located in Chattanooga, TN.

#### Easterseals

[www.easter-seals.org](http://www.easter-seals.org)

Easterseals is a national organization that helps individuals affected by disability. Services may include speech and hearing. For a description of services in your area, contact your state office or the national office.

#### The March of Dimes

[www.modimes.org](http://www.modimes.org)

The March of Dimes usually supports programs rather than individuals. But local chapters may be able to direct families to other organizations that can help with funding. Local chapters are usually listed in the telephone directory or online.

### Further Information on Funding

#### Families USA

[www.familiesusa.org](http://www.familiesusa.org)

202-628-3030

Families USA is a nonprofit, nonpartisan organization that works for high quality, affordable health care for all Americans. The website provides information on current legislation, a state-by-state guide, and a resource library.

#### CleftAdvocate

[www.cleftadvocate.com](http://www.cleftadvocate.com)

CleftAdvocate is a parent-run website that offers advice and sample letters for fighting insurance denials for cleft services. It also provides general information about cleft lip and palate.

#### Family Voices

[www.familyvoices.org](http://www.familyvoices.org)

888-835-5669

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

#### National Organization for Rare Disorders (NORD)

[www.rarediseases.org](http://www.rarediseases.org)

800-999-6673

844-259-7178 espanol

NORD is an advocacy organization for people with rare disorders. NORD provides education, advocacy, research, and patient services. It also has an assistance program for certain prescription medications.

#### Patient Advocate Foundation

[www.patientadvocate.org](http://www.patientadvocate.org)

800-532-5274

The Patient Advocate Foundation provides legal services for patients with issues related to access to care, medical debt, and job retention. The Foundation also educates patients about managed care, insurance policies, and public policy issues that affect coverage. Site information is available en espanol.



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Revised November 2019