

# FACES: The National Craniofacial Association 1-800-332-2373

## How do I pay the bills?

Dealing with the cost of medical treatment for your child can be overwhelming. The information below can help get you started. There are several sources of funding available to cover the cost of medical care for your child.

- Health Insurance
- Public Programs
- Private and Non-Profit Agencies
- Other Alternatives

### Health Insurance

Private and group health insurance will usually pay at least part of the cost of treatment of craniofacial conditions. The following are important considerations when dealing with health insurance companies.

- Does your child have a specific diagnosis?
- Does your health insurance plan address your child's needs?
- Are there limitations on services?
- Are there waiting periods for pre-existing conditions?
- If you are involved with a managed care (HMO or PPO) organization, will they cover your child's doctors if they are not in the group?

**Always** request a copy of your health insurance policy, not the benefits summary brochure. The brochure is not specific enough.

**Remember**, the insurance company works for you. **You pay them** to provide a service. When dealing with the insurance company, be sure to:

- Get an 800 number; if they don't have one, ask them to call you back.
- Every time you call, write down the date, the name, position and telephone number of the person you spoke with, as well as what you discussed.
- Ask to be assigned a case manager from the insurance company. This person will act as your advocate through the insurance maze, as well as become more familiar with your child's condition, in an effort to speak on his or her behalf to the company's decision makers.

### Public Programs

There are a variety of federal and/or state funded programs which may be able to help your child receive the care he/she needs. A few are:

- Medicaid
- State Children's Health Insurance Program
- Maternal Health & Child Health Block Grants
- Children's Health Insurance Program (CHIP)

These programs are a good source of information. They are required by the government to have toll-free numbers. There is a state administered program called "Insure Kids Now!" which helps with health insurance for children with medical and financial needs. See the back for more info!

When dealing with public programs, be sure to:

- Get a written list of benefits, restrictions, and eligibility criteria.
- Find someone within the program to help you through the process. Make him or her aware of your child's needs.
- Get involved on the advisory board for the program; you will be able to more directly affect the program.
- Get your legislator involved.

### Private and Non-profit Agencies

There are numerous private and non-profit agencies which may be able to help out. Many organizations deal only with a specific disability or illness. Some organizations in your community could be:

*Shriner's Hospitals, Lions Clubs, Police Benevolent Associations, Civitan Clubs, Kiwanis Clubs, Sertoma Clubs, Churches, Rotary Clubs, and Junior League Organizations.*

If they cannot help you, always ask if they can refer you to another organization that might be able to help.

### Other Alternatives

There are several other things you can do to help pay for and/or reduce medical bills:

- Find out if your local hospital or health care center has a private endowment fund.
- Itemize out-of-pocket medical expenses on your tax return.
- Ask your employer to set up a health care reimbursement account.
- Negotiate reduced payment with the hospital or doctors.
- Identify disability related organizations in your community.
- When applying for assistance, be sure to emphasize that your child's health needs affect the entire family.

### **Grants for Families Struggling with Health-Related Expenses - Children 16 and under**

The United Healthcare Children's Foundation offers to help children who need critical health care treatment, services or equipment that is not covered by health insurance. The United Healthcare Children's Foundation funds expenses such as speech therapy, physical therapy, occupational therapy, prescription medications and medical equipment. Grants are up to \$5,000 per child, and families must meet certain economic requirements. Applications and more information are available on the UHCCF website at: <http://uhccf.org>. Click on 'To Apply' for information on the grants and application process.

**Be proactive! Become an advocate for your child. Speak out! It is the only way in which health care reform will occur.**

## Am I Alone?

No! There are many families and organizations that will be glad to talk with you and help you with information and support. Don't forget books, videos, and even websites. Listed below are a few resources to get you started.

FACES: The National Craniofacial Association  
P. O. Box 11082  
Chattanooga, TN 37401  
(800) 332-2373  
email: [faces@faces-cranio.org](mailto:faces@faces-cranio.org)  
web: [www.faces-cranio.org](http://www.faces-cranio.org)

*We provide financial support for non-medical expenses to patients traveling to a craniofacial center for treatment. Eligibility is based on financial and medical need. Resources include newsletters, information about craniofacial conditions, and networking opportunities.*

### Hill Burton Act

[www.hrsa.gov/gethealthcare/affordable/hillburton](http://www.hrsa.gov/gethealthcare/affordable/hillburton)

*This legislative act provides funds for indigent care at hospitals where federal monies were used for construction. The hospital admissions office has information on the availability of these funds and the guidelines for eligibility.*

National Association of Insurance Commissioners  
444 N. Capital Street NW - Suite 701  
Washington, D.C. 20001  
(202) 471-3990  
[www.naic.org](http://www.naic.org)

*Provides information on the Insurance Commissioner in your state. The state insurance commissioner is the governing body that regulates the insurance companies doing business in your state. This office can assist you in determining if your insurance company is following all the rules and regulations as set forth in your policy.*

National Health Law Program  
1444 I Street, NW - Suite 1105  
Washington, DC 20005  
(202) 289-7661  
[www.healthlaw.org](http://www.healthlaw.org)

*Provides extensive information on health care laws affecting families of children with special needs.*

Cleft Advocate  
P.O. Box 751112  
Las Vegas, NV 89136

(702) 769-9264

Email: [Debbie@cleftadvocate.org](mailto:Debbie@cleftadvocate.org)

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

*This website, under the direction of Deb Oliver, focuses on a number of financial issues of cleft repair and treatment. Included are sample letters to assist parents in appealing insurance decisions, as well as to assist with state Medicaid issues. Most of this is applicable to other craniofacial disorders.*

### Children's Health Insurance Program (CHIP)

Insure Kids Now!

(877) 543-7669 (toll-free)

[www.insurekidsnow.gov](http://www.insurekidsnow.gov)

*Established in 1997 to help children whose families earn too much to qualify for Medicaid, but can not afford private insurance. Eligibility for programs varies among states. To find out about eligibility, call the toll free number, Monday through Friday between 8am and 4pm.*

### American Speech-Language-Hearing Association

2200 Research Blvd

Rockville, MD 20850

800-638-8255

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

*Visit the website or call for a checklist developed by this organization outlining how to approach an employer to request that health plan coverage for speech and hearing services be added or improved.*

### Patient Advocate Foundation

421 Butler Farm Road

Hampton, VA 23666

(800) 532-5274

email: [help@patientadvocate.org](mailto:help@patientadvocate.org)

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

*Patient Advocate Foundation is a national, non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment, and preservation of their financial stability. Patient Advocate Foundation serves as an active liaison between patients and their insurer, employer and/or creditors to resolve insurance, job retention, and/or debt crisis matters relative to their diagnosis through case managers and attorneys.*

## SAMPLE LETTER TO USE WHEN CONTESTING INSURANCE COMPANY PAYMENT

(FILL IN THE BLANKS AND SEND WHEN YOU BELIEVE YOUR INSURANCE  
HAS NOT PAID EVERYTHING IT SHOULD)

(Your Name)  
(Your Address)  
(Your City, State, and Zip)  
(Date)

(Your Insurance Company)  
(Your Insurance Company's Address)  
(Your Insurance Company's City, State, and Zip)

ATTENTION: Claims Review Committee  
RE: Claim Number 000000

I recently received notice that you did not make a full payment on this claim. I am preparing my records to appeal this decision and am asking you to provide the following information in writing as soon as possible:

- 1) The reason, in detail, this claim was not paid in full;
- 2) The section number and paragraph referenced in my policy which provide the reason that this claim was not paid in full;
- 3) The name of the party who reviewed this claim;
- 4) All conditions which must be met which would entitle this claim to be covered in full.

Please provide in your response, the name, address, and phone number of the person responding, along with the name of his or her supervisor.

Sincerely,

(Your Name)

cc: (Name of your insurance Plan Administrator)

**SAMPLE LETTER TO USE WHEN INSURANCE  
COMPANY DENIES CLAIM**

(FILL IN THE BLANKS AND SEND WHEN YOUR INSURANCE COMPANY WILL NOT PAY ON A CLAIM)

(Your Name)  
(Your Address)  
(Your City, State, and Zip)  
(Date)

(Your Insurance Company)  
(Your Insurance Company's Address)  
(Your Insurance Company's City, State, and Zip)

ATTENTION: Claims Review Committee  
RE: Claim Number 000000

You recently denied payment on this claim. I am preparing my records to appeal this denial and wish you to provide the following information in writing as soon as possible:

- 1) The reason, in detail, this claim was denied;
- 2) The section number and paragraph referenced in my policy which provide the reason for this denial;
- 3) The name of the party who reviewed and denied this claim;
- 4) All conditions which must be met which would entitle this claim to be covered.

Please provide in your response, the name address, and phone number of the person responding, along with the name of his or her supervisor.

Sincerely,

*(Your Name)*

cc: (Name of your insurance Plan Administrator)

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## SAMPLE LETTER OF COMPLAINT TO YOUR STATE'S INSURANCE COMMISSIONER

(FILL IN THE BLANKS AND SEND WHEN YOU ARE NOT SATISFIED WITH ANY ASPECT OF YOUR  
INSURANCE COMPANY'S PROCEDURES)

(Your Name)  
(Your Address)  
(Your City, State, and Zip)  
(Date)

(Your State's Insurance Commissioner)  
(Your Commissioner's Address)  
(Your Commissioner's City, State, and Zip)

ATTENTION: Complaint Investigations  
RE: Claim Number 000000 (or other referencing information)

This is to inform you that in my opinion, (*Name of Insurance Company*) is not complying with the contract agreements in my health insurance policy, (*Policy Number, Group Number, and any other identifying numbers of your policy*).

I am filing a complaint because I believe (*Name of Insurance Company*) has unjustly denied the above referenced claim for (*Type of medical services*).

I am enclosing copies of the section of my insurance policy which provides for this coverage, and all correspondence between me and (*Name of Insurance Company*) for your convenience.

Please investigate this matter and notify me of your response.

Sincerely,

(Your name)  
(Telephone Number)

cc: (Name of your insurance Plan Administrator)  
(Name of your Employer)  
(Your Attorney)

# Birth Defect Research for Children, Inc. Fact Sheets

## How to Make Health Insurance Work for You

If your child is born or later diagnosed with birth defects or disabilities, one of the first things you should do is check your health insurance policy. The benefits in your policy may determine the quality of health care your child receives now and in the future.

If you do not have any health insurance coverage, you need to know what your options are for funding your child's health care.

### Types of Insurance

**Individual:** If you work for a business with fewer than twenty employees or you are self-employed, you may have an individual insurance policy. If you are already insured at the time your child is born, your child should be fully covered under an individual policy. But, if your child's care becomes costly, your insurance may be canceled or your premiums may be raised since you are not part of a large group. If your insurance is canceled, you may have other options for health coverage depending on the state in which you live.

**Group Health Insurance:** Most companies with 20 or more employees offer group health insurance benefits. Since the coverage for high-cost patients is shared by all members of the group, your child may have complete coverage even for pre-existing conditions. In recent years, however, some group policies have developed categories of acceptable coverage. There may be a waiting period for coverage of pre-existing conditions or you may not be accepted for group coverage because the estimated costs of your child's future medical care are too high.

**COBRA:** If your family has been covered by a group health insurance policy and you lose your job, you may still have between 18 and 36 months of continued insurance coverage. A special law called the Constitutional Omnibus Budget Reconciliation Act (COBRA) requires that all employers of 20 or more people provide continuation of insurance coverage for terminated or laid-off employees and their dependants for 18 to 36 months. COBRA requires you (the employee) to pay up to 100 percent of the insurance premium.

**High Risk Insurance Pools:** If you did not have any insurance coverage at the time your child was diagnosed with birth defects or disabilities, you may be able to join a "High Risk Insurance Pool." A risk pool is a comprehensive health insurance association that has been set up by a state working with insurance carriers. Risk pools sell health insurance to people who have been denied coverage because of serious medical conditions.

To find out whether your state has high risk pool insurance available, call your state Insurance Commissioner's office. You can find the number in the State Government blue pages section of your phone book.

## Who Qualifies For A High Risk Pool

To join a high risk insurance pool, an applicant must be a state resident and meet one of the following requirements (may vary by state):

- Rejected for coverage by one private insurance company (FL, IN, MT, may require two), or
- Not eligible for Medicare, or
- Received a notice of benefit reduction, or
- Had a premium increase that was more than the rate for pool coverage, or
- Had a restriction added to the policy for a pre-existing condition, or
- Suffer from certain chronic conditions such as cancer that automatically qualifies for risk pool coverage.

Although high risk insurance pools offer coverage for catastrophic medical costs, there are some disadvantages. The premiums may range into thousands of dollars for the highest risk categories. The deductibles may be as much as \$2,000 annually per person. And there may be a waiting period of six months to a year before some pre-existing conditions are covered.

In difficult economic times, some states have cut off enrollment in high risk insurance pools. To find out the status of risk pools in your state, call the office of your state's insurance commissioner.

**Catastrophic Insurance Pools:** Some states have created special catastrophic pools to protect families against medical expenses that may greatly exceed their income. For example, Rhode Island's Catastrophic Health Insurance Program (CHIP) will pay for medical expenses once a certain deductible has been met based on a percentage of the applicant's income spent on medical services. New Jersey has created the Catastrophic Illness in Children Relief Fund that assists families of children ages 18 or younger whose uncovered medical expenses exceed 30% of the family's income up to \$100,000.

## Find Out About Your Options

The availability of high risk insurance pools varies from state to state and may change as a state's economy changes. Be sure to contact the insurance commissioner's office to find out the current status of these programs in your state.

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## Resources

Birth Defect Research for Children, inc.  
930 Woodcock Road, Suite 225  
Orlando, FL 32803  
Phone: (407)245-7035  
<http://www.birthdefects.org>

Federation of Children with Special Needs  
95 Berkeley Street, Suite 104  
Boston, MA 02116  
1-800-331-0688  
(617)482-2915  
<http://fcsn.org>

National Organization for Rare Disorders (NORD)  
P. O. Box 8923  
New Fairfield, CT 06812  
1-800-447-6673  
Phone: (203)746-6518 / Fax: (203)746-6481  
<http://rarediseases.org/for-patients-and-families/help-access-medications/financial-assistance/>

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