

# ***F*inancial Assistance and Other Resources**

Financial resources to help in paying all or part of the costs of treating a person with a cleft lip and/or palate fall into three general categories: private and group health insurance; federal and state resources; and private and nonprofit agencies, foundations, and local service organizations. The most important thing to remember is that there are funds available, and people available, to help the person with a cleft get the care he or she needs.

## **Health Insurance**

Private and group health insurance will usually cover a portion of the cost of treatment of a cleft lip or palate after a deductible is met. Check your health-care plan or call your insurance company for specific coverage information. When choosing health insurance policies, check into coverage of not only surgery and medical care but also dental care and services such as hearing testing, speech and lan-

guage testing and treatment, and psychological testing and/or counseling. If you are being denied the coverage benefits set forth in your policy, call and advise your State Insurance Board.

### ***Seeking Insurance from Private Companies***

Without the active and thorough involvement of parents in the claims process, insurance companies do not always fulfill their contractual obligations in a complete or timely way. "Insurance Issues," an article written by Teresa Robinson that appeared in *About-Face*, August/September 1992, says it all.

*Seventeen years ago, on the day my son was born, I had no idea how much my life would change. A child with special needs takes an incredible amount of energy, time, care, and last, but not least, money!*

*Eric was born with a bilateral cleft lip and palate. Through his 28 surgeries, I have dealt with the insurance company on almost every claim. The first few surgeries were covered by Crippled Children's Services (now usually called Children's Special Health Services [CSHS] in most states) because my husband was in school and we had very little income. I had checked with other service organizations, but was unable to receive any assistance. Since 1985, I have kept accurate records. The insurance companies have disputed almost every claim. The following are but a few examples of conditions related directly to his birth defect that we have had to seek legal counsel to get resolved.*

*Eric needed a hearing aid. The insurance company claimed that they would only pay for this if Eric had been in an accident and the hearing aid was intended to restore his hearing, not to give him hearing.*

*Eric had speech therapy for ten years. The same rules held for this therapy as for the hearing aid, and*

*the insurance company would not provide for speech therapy, regardless if it was due to his birth defect or not.*

*Eric has needed braces and other orthodontic appliances. The dental insurance has paid for some, but Eric has now reached the coverage limit. The medical insurance refuses to pay. This orthodontic battle is now before the city's legal department. The latest orthodontic work is in preparation for upcoming surgery and is a necessary step before this can occur. The insurance company states that treatment is orthodontic and denies coverage.*

*Presently, I deal with a self-insured employer. My motto has become "Don't accept no for an answer." After the first denial, I would write to the broker again, enclosing a doctor's letter. If coverage is still denied, I suggest going directly to the employer, who can overrule the broker. If all else fails, see an attorney. Each claim dispute can take anywhere from six months to two years to be processed.*

## Federal and State Government Resources

### **Medicaid**

Medicaid (Title XIX of the Social Security Act of 1966) is a federal assistance program that covers most of the cost of medical care for people with low incomes who require hospital or physician services or certain laboratory and x-ray procedures. In some states, services such as treatment for speech or hearing defects may be covered. Apply in the county offices of your state Social Service, Welfare, or Human Resources Departments.

***Children's Special Health Services (CSHS)***

Formerly called the Crippled Children's Program, CSHS provides comprehensive medical care to children under the age of 21 who have congenital or acquired physically handicapping conditions. Specific medical and financial criteria have to be met by the applicants before financial assistance is approved. Applications are available through the director of Children's Special Health Services. Contact your state Department of Health for further information or for the locations of agencies or medical facilities in your community that provide these services.

***Vocational Rehabilitation Services***

These services are designed for persons sixteen years of age or older with emotional, mental, physical/medical, and/or developmental disabilities that hinder their prospects for employment. Call your state Department of Human Resources or Welfare Office for assistance in locating the nearest VR services.

***Champus***

Champus is a federally funded medical benefits program for members of the uniformed services and their dependents. For more information, contact the health benefits administrator at the nearest military installation.

***The Federal Hill-Burton Act***

These funds provide for indigent care at hospitals for which federal monies were used for construction. Your hospital's admissions office will have informa-

tion on the availability of these funds and guidelines for eligibility.

***Public Law 99-457***

This law better enables parents to secure services for their children younger than two years of age who have identifiable handicaps. The law is scheduled to be in full operation by 1994. Each state has developed its own implementation plan. For more information, contact your state's Education Department or Department of Health and Rehabilitative Services.

***US Department of Health and Human Services,  
Maternal and Child Health Bureau, The Pro-  
gram for Children with Special Health Care  
Needs***

To participate in this program, public schools must offer an assessment and a written Individualized Family Service Plan (IFSP) for the child and parents. Educational services may include: special education, speech and language pathology, audiology, psychological services, parent training, and medical services for diagnostic purposes to enable the child to benefit from early intervention. For more information, write to: US Department of Health and Human Services, Maternal and Child Health Bureau, 5600 Fisher Ln, Rockville, MD 20857.

## Private and Nonprofit Agencies, Foundations, Service Organizations, and Support Groups

### ***The Smile Train***

The Smile Train is an international children's charity launched in 1999 which is dedicated to helping the millions of children in the world suffering from cleft lip and palate. Its comprehensive approach to the problem of clefts involves free surgery for children, free training for doctors, and research to help find a cure. The Smile Train is committed to empowering surgeons and medical professionals in developing countries to meet the cleft care needs of their own communities. The organization is supported solely by individuals and private foundations, and 100% of donations go directly to programs. For more information, visit their website at [www.smiletrain.org](http://www.smiletrain.org); write to The Smile Train, 245 Fifth Avenue, Suite 2001, New York, NY 10016; or call (877) 543-7645.

### ***The Cleft Palate Foundation***

This foundation is the fundraising, educational, and communication component of the American Cleft Palate Craniofacial Association, providing free information for parents and patients about such topics of interest as local treatment facilities and parent support groups. For more information, write: The Cleft Palate Foundation, 104 S. Estes Drive, Suite 204, Chapel Hill, NC 27514; or call (919) 933-9044 or 1-800-24-CLEFT. (See Appendix D for publications.)

***The Miami Craniofacial Anomalies Foundation***

The MCAF supports research and education in cleft palate and other craniofacial malformations. Donations may be sent to: The Miami Craniofacial Foundation, 6601 SW 80th St, South Miami, FL 33143; or call (305) 667-3126 for more information.

***The National Association for the Craniofacially Handicapped (FACES)***

FACES provides financial assistance for supportive services, eg, transportation, food, and lodging to families of individuals who are receiving treatment for craniofacial deformities resulting from birth defects, injuries, or disease. For further information write to: FACES, PO Box 11082, Chattanooga, TN 37401; or call (423) 266-1632.

***The Easter Seal Society***

Easter Seal is a nonprofit organization serving physically or developmentally disabled children and adults. Although the Society's primary focus is on patients with cerebral palsy and similar neurologic conditions, local chapters provide a variety of other services including speech and hearing assistance. For a description of Easter Seal services in your area, contact your state office or write: The National Easter Seal Society, 2023 W Ogden Ave, Chicago, IL 60612. (See Appendix D for publications.)

***Grottos of America***

Grottos of America provides dentistry to the handicapped. Patients must be under eighteen years of age to receive assistance from this organization. In addi-

tion they must have one of the following conditions: cerebral palsy, muscular dystrophy, mental retardation, or myasthenia gravis. For further information about the organization's national headquarters, write: Grottos of America, 1696 Brice Rd, Reynoldsburg, OH 43068; or call (614) 860-9193.

### ***La Leche League International***

La Leche League, a society consisting of lay and professional members, provides accurate information and a variety of support services to parents and health-care professionals committed to breast feeding. For more information write: La Leche League International, 9616 Minneapolis Ave, Franklin Park, IL 60131; or call (800) 423-3262.

### ***The March of Dimes Birth Defect Foundation***

The March of Dimes supports programs designed to prevent birth defects and promotes research, professional education, and treatment. Each local chapter determines how its local funds are to be allocated. While chapters are not encouraged to use funds for the treatment of individuals, a local chapter may assist families in meeting the costs of treatment when no other funds are available. Local chapters of the March of Dimes are listed in the telephone directory. For more information write: The March of Dimes, 1275 Mamaroneck Ave, White Plains, NY 10605. (See Appendix D for publications.)

### ***The Natural Father's Network***

This organization advocates for fathers of children with disabilities. For more information write: The Natural Father's Network, Kinderling Center, 16120 NE Eighth

St, Bellevue, WA 98008; or call (425) 747-4004, extension 218.

### ***Parent Training Information Projects (PTI)***

Each state has a PTI office. By contacting a regional office, parents of children with special needs can get information and training and can network with others in their state. To get the phone number of your state office, contact: The Federation for Children with Special Needs, (617) 236-7210, and ask for the CAPP (Collaboration Among Parents and Health Professionals) project; or write: FCSN, 95 Berkeley St, Boston, MA 02116.

### ***Local Service Organizations***

The Lions, Sertoma, Kiwanis, and Civitan Clubs sometimes provide emergency one-time financial aid to community members in need if funds are available. Local churches and church-related groups, such as the Knights of Columbus and Masons, may also serve as resources. Telephone numbers for these organizations can usually be found in the Yellow Pages under the heading, "Clubs, Fraternal Organizations, and Religious Organizations."

## Health-Care Financing News

### ***Bibliography on Health-Care Financing***

To request a copy, write: Collaboration Among Parents and Health Professionals (CAPP), Federation for Children with Special Needs, 95 Berkeley St, Boston, MA 02116; or phone (617) 236-7210.

### ***Health Insurance Resource Guide***

The Genetic Alliance has recently published a booklet on understanding the language of health insurance in plain English. Contents include: "The Pre-Existing Condition Dilemma," "Obtaining and Keeping Health Insurance," "Listings of States with High Risk Insurance Pools," "Sample Letters to Contest Insurance Company Decisions," and "Health Insurance in Foreign Countries." For more information about health insurance, or to obtain a copy of this booklet, contact: Martha Volner, Genetic Alliance, 4301 Connecticut Avenue NW, Suite 404, Washington, DC 20008-2304; or call 1-800-336-GENE.

### ***New Legislation Mandating Insurance***

Legislation recently passed in California, Colorado, Florida, Indiana, Louisiana, Maryland, Minnesota, North Carolina, South Carolina, Texas, and Wisconsin mandates that insurance companies provide continuous hospital, medical, surgical, dental and speech therapy coverage for the care of children with congenital deformities, including those whose

families transfer coverage to another third-party payer. The law specifically targets private insurance companies that claim these anomalies are pre-existing conditions. In the past, if parents switched jobs or changed carriers they risked losing coverage, an all too grimly familiar story.

### ***SSI Benefit Denials Under Review***

Nearly one-half million children with disabilities who were denied Supplemental Security Income (SSI) benefits during the last ten years are eligible for reevaluation of their claims as a result of the US Supreme Court's recent ruling in *Sullivan v. Zebley*. Parents and guardians of children with disabilities who were denied benefits, or whose benefits were terminated between January 1, 1980, and February 27, 1990, were sent letters in July 1991 explaining their eligibility for review. Those who have not received a letter, but believe they are eligible, should contact their local Social Security offices.