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Resources

A Guide for Parents of Children with Craniofacial Conditions



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RESOURCES

A Guide for Parents of Children with Craniofacial Conditions

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The purpose of this guide is to help parents of children with facial differences access information, resources, and services to support their children's special needs. Educating yourself about your child's condition and available resources will help you to make decisions related to your child's care. We want to empower you to be an effective advocate and to make you feel less alone.

Your child's health care team is the best place to start when you are looking for information or assistance. However, there are many governmental and non-profit organizations that provide services that may be of benefit to you and your family. This guide is meant to supplement the information provided by your child's health care team and to provide a starting point from which to explore services that address your family's needs.

While every effort has been made to ensure that the information in this guide is accurate, we recommend that you contact the appropriate organizations to make certain you have the most up-to-date information available.

CHAPTER 2

ACCESSING COMMUNITY RESOURCES

There are many sources in your own community where you can obtain information about your child's condition and care. Some places to start are as follows:

Health Care Providers

Your child's health care providers (e.g., pediatrician, craniofacial team) are an excellent resource for the most accurate, current, and relevant information regarding your child's condition and care.

Social Workers

Social workers at local hospitals, schools, and community social service agencies usually have information about resources in your area. They can direct you to entitlement programs, support networks, and organizations that may be helpful. Many social workers work with children and will be able to connect you to resources, provide your family with emotional support, and answer some of your questions.

Public Libraries

Your local public library is another good source of information. Many libraries have designated sections for information regarding children with special needs. Librarians can direct you to materials on facial differences and related resources. In addition, most libraries have computers with Internet access and typically have support personnel available to assist you with computer use and with performing searches for information and resources.

Academic and Medical Libraries

Academic and medical libraries contain books, journals, databases, and web-based resources that are written for professional readers. These materials may be difficult to understand without a medical background or education. However, most of the information found in academic and medical libraries has been evaluated for accuracy.

Telephone Books

The telephone book can be a helpful aid when looking for assistance and information. You can find referral services, government agencies, and organizations in the Yellow Pages listed by key terms.

Local Government Organizations

Local community boards can also be helpful. Contact your town or city government office to find out how to reach your local or state officials and your local health department. Local officials and health department personnel can identify and help you access resources in your area.

Religious Organizations

Your place of worship can be a good place to learn what is available in your community.

Internet

More and more people find and share information on the Internet. While you may not own a computer, you probably know someone who does. In most communities, you can access the Internet in a school, community center, or local library. The Internet provides access to information on a wide range of subjects. Foundations supporting those with facial differences often have websites where parents can find useful information, and many governmental organizations have websites where you can learn about your child's rights and benefits (see Chapters 3-11). However, you should be cautious about what you read on the Internet, especially in discussion forums. Whereas information you receive from academic sources has typically been reviewed and evaluated for its accuracy, the Internet can be a free-for-all. You may encounter sites where people share personal experiences and provide information that may or may not be correct. Discuss the web-based information you find with your child's health care providers so that they can help you determine if the information is relevant to your child's particular situation. Your health care team may be able to refer you to a list of recommended websites that other parents have found useful.

Peer Networks

Parents of children with facial differences often have the most up-to-date information on what services and resources have been helpful to them. You can meet other parents through your child's treatment team as well as through parent-to-parent organizations. Networking with other parents can be done in person, over the telephone, or via email.

HELPFUL TIPS WHEN LOOKING FOR RESOURCES:

- Choose a method of organizing the information you obtain. You can write your information on a notepad or in a journal or store it in files. Keep all of your information in one place so that it is easily accessible and available when you need it.
- Make a list of questions as you think of them so that you do not feel “on the spot” or distracted when engaged in a conversation with personnel from an office or organization. Keep a pen in a designated place, such as next to the telephone or with your notebook, so that it is handy when you need it.
- Thank the people or organizations you contact, either over the phone or in writing, to motivate future cooperation. Courtesy can go a long way!
- Ask for people’s names and confirm telephone numbers! This information comes in handy when you have to call back or if you get disconnected.
- Paper trails can be important. Document what you were told, when you were told it, and the name of the person with whom you spoke. Ask for information in writing.
- Everyone has a boss. Start at the bottom and work your way up. If you are not satisfied with someone, you can politely ask to speak to that person’s supervisor for clarification.
- Waiting lists are a reality. Put your child on a list; you never know when your child may need a particular service or program. You can always take your child off of a list.
- Be prepared to describe your child’s condition. The people you speak with may not be familiar with the details or may have preconceived ideas about the condition.
- Offer to send a picture of your child or family. Sometimes putting a face to a name can help to foster a personal connection.
- If at all possible, try to make an appointment to meet in person. Being able to “tell your child’s story” in a relaxed manner, at a scheduled time, can be better than a rushed telephone call.
- Ask who will have access to the information you provide about your child. Some organizations ask that you sign a release of information form that gives them permission to speak with other agencies on your behalf and about your child’s medical condition.
- Make copies of documents that you are asked to send to individuals or organizations. Never send originals in the mail, and if someone takes your originals to make copies, always make sure that the originals are returned to you.
- Be patient! Sometimes it takes a number of telephone calls and days of waiting for return calls before you get to the right person or find the information and services you need. Ask if and when you should call someone again or when you can expect them to call you.
- This chapter gave you some guidelines on how to access information in your community. In the following chapters, we will provide you with information on specific resources for children who have facial differences.

CRANIOFACIAL CENTERS

A child born with a facial difference may experience a number of physical and emotional challenges that need special attention and care. This care usually requires the expertise of multiple professionals from many different medical areas an interdisciplinary team to ensure that all problems are addressed and that your child's care is coordinated. Such interdisciplinary care is often provided at a craniofacial center. Below are some common questions and answers related to craniofacial centers:

1. What is a craniofacial center?

A craniofacial center is a facility at which a team of specialists works together to provide coordinated care to patients with facial differences. These centers are usually located in a hospital setting, and address both facial differences that are congenital (present at birth) and those resulting from another medical problem or injury. A craniofacial center is special because it can address the various problems associated with your child's condition, often in one institution.

2. What are the advantages of having my child followed at a craniofacial center?

A craniofacial center has a team of specialized professionals from a variety of fields (see Chapter 4) which may include plastic and reconstructive surgery, oral and maxillofacial surgery, dentistry, orthodontics, otolaryngology (ENT - ear, nose, and throat), ophthalmology, nursing, speech and language pathology, social work, psychology, and genetics counseling, among others. The purpose of craniofacial centers is to provide comprehensive and coordinated treatment for patients with facial differences. Members of the craniofacial team will develop an individualized treatment plan for your child and work with you during every phase of treatment. The size of your team depends upon your child's facial difference and his or her individualized treatment plan. This team approach ensures that all aspects of the treatment plan are coordinated and appropriate for your child's specific needs.

3. When should my child be evaluated at a craniofacial center?

Your child should be evaluated at a craniofacial center as soon as you suspect a facial difference or if there is a family history of facial differences. Early evaluation is advised in order to determine if your child's facial difference may interfere with bodily functions such as eating, drinking, and breathing. The goal is to address potential problems, minimize the risk of complications, and maximize the likelihood that your child will reach developmental milestones.

4. How long will my child need to be followed by a craniofacial center?

Your child's individualized treatment plan will determine how long your child will need to be followed by a craniofacial center and will vary depending on your child's condition. Sometimes there may be long periods of time in between visits to the craniofacial center. Your child may need to be a certain age or level of emotional and physical development to have a surgical procedure. Your child's team will remain available should you have any questions or concerns about your child and his or her care, even if your child is not currently in treatment.

5. Will the cost of my child's care by the craniofacial team be covered by my health insurance plan?

Health insurance policies vary. Determining what is and is not covered can be a complicated and overwhelming process regardless of your family's specific health insurance policy. We recommend that you communicate with your health insurance provider directly and educate them about your child's condition. Do not assume that health insurance providers understand the details of your child's condition. The more information your health insurance company has, the more you will be able to work together. It is important to emphasize to the health insurance company that your child's treatment and possible need for surgery are not for cosmetic reasons. It may be helpful to submit a letter of medical necessity from your child's physician(s) to your health insurance company so that they have a better understanding of your child's condition and treatment plan.

It is also important to inform the craniofacial center about your health insurance coverage. The craniofacial center will be prepared to tell you the costs of having your child evaluated by their team. Craniofacial centers may work with only certain health insurance companies or have different ways of handling their fees when working with various health insurance companies. The craniofacial center will advise you of the health insurance plans for which they are a participating provider. Before your first appointment, inquire with your health insurance plan and the craniofacial center about possible copays, deductibles, co-insurance, and other fees that you will be responsible for at the first visit so you are prepared when you arrive.

Discuss your financial concerns when you make your appointment. You will find that many craniofacial centers are prepared to work with you on financial issues because they want to ensure that children receive the quality care that they need.

6. How do I find a craniofacial center?

Begin your search for a craniofacial center by speaking with your child’s pediatrician or other health care professional. The American Cleft Palate-Craniofacial Association (ACPA) has developed standards for craniofacial centers to ensure that teams are “comprehensive, culturally sensitive, specific to the needs of the individual and readily accessible.” The ACPA has also developed specific guidelines for the care of children and adolescents with facial differences. If possible, have your child evaluated by more than one craniofacial team before choosing your child’s team.

If a craniofacial center is not located near your home, have your child evaluated by the team that is closest to you. Although the overall care of your child will be managed by the craniofacial team, certain aspects of the treatment plan can be implemented by local physicians and hospitals. The craniofacial team may make referrals to clinicians in your community and coordinate and oversee your child’s local care. This arrangement will decrease the number of visits you need to make to the craniofacial center. You may inquire about travel arrangements at the time you schedule your child’s appointment. For more information about travel assistance, please refer to Chapter 9, Section 4.

The following organizations may assist you in locating a craniofacial center:	
American Cleft Palate-Craniofacial Association(ACPA) 1504 East Franklin Street, Suite 102 Chapel Hill, NC 27514 (919) 933-9044 www.acpa-cpf.org	CleftAdvocate P.O. Box 751112 Las Vegas, NV 89136 (888) 486-1209 (702) 769-9264 www.cleftadvocate.org
The ACPA is an “international non-profit medical society of health care professionals who treat and/or perform research on birth defects of the head and face.” One of the main objectives of the ACPA is to promote communication and cooperation among health care professionals from different specialties.	CleftAdvocate is an Ameriface program. CleftAdvocate’s mission is to educate and encourage families affected by cleft lip/palate or other facial differences. The program provides educational opportunities, support networks, advocacy guidelines, and state-by-state resources.
Ameriface (previously AboutFace USA) P.O. Box 751112 Las Vegas, NV 89136 (888) 486-1209 www.ameriface.org	Cleft Palate Foundation (CPF) 1504 East Franklin Street, Suite 102 Chapel Hill, NC 27514 (919) 933-9044 CLEFTLINE (800) 24-CLEFT (800) 242-5338 www.cleftline.org
Ameriface is a national organization that provides information and support to persons with facial differences and their families. Its outreach program connects families with community-based resources, such as cleft/craniofacial teams and centers.	The CPF, the public service branch of the ACPA, is a “non-profit organization dedicated to optimizing the quality of life for individuals affected by facial birth defects.” The CPF produces free publications and runs the CLEFTLINE, a toll-free hotline that provides information on clefts and other facial differences. Callers can request or go online for information about cleft palate/craniofacial treatment teams and parent-patient support groups in their area.
Children’s Craniofacial Association (CCA) 13140 Coit Road, Suite 517 Dallas, TX 75240 (800) 535-3643 www.ccakids.com	FACES: The National Craniofacial Association P.O. Box 11082 Chattanooga, TN 37401 (800) 332-2373 www.faces-cranio.org
CCA is a non-profit organization that provides support and information to help address “medical, financial, psychosocial, emotional, and educational concerns” related to facial differences. The organization offers detailed information about specific facial differences, treatment centers, and family networking, as well as links to other web-based resources.	FACES: The National Craniofacial Association is a non-profit organization that serves children and adults with facial differences. The organization provides information on many topics and resources, including craniofacial centers across the United States.

CHAPTER 4

THE CRANIOFACIAL TEAM

Chapter 3 of this guide informed you about craniofacial centers and the importance of having a team of specialists involved in your child's health care. This chapter explains who is part of that team.

The members of your child's craniofacial team will depend on your child's medical condition and the specialties available at your child's craniofacial center. If your child requires the services of a health care professional who is not a member of your child's craniofacial team, you will be given a referral to a professional whom the team recommends. The craniofacial team will provide your child's history and the reason for the referral to that health care professional. Although that health care professional may not be a "formal" member of the craniofacial team, the team and the additional provider will be in close communication to ensure that all aspects of your child's medical condition are evaluated and addressed.

The craniofacial team does not take the place of your child's pediatrician, who will still manage your child's routine health. Your child's pediatrician should be informed of the treatment plan developed by the craniofacial team so that all of your child's health care services may be coordinated.

Your child's craniofacial team may include the following health care professionals:

- **Audiologist** - a health care professional who diagnoses, treats, and manages individuals with hearing loss or balance problems. An audiologist fits and dispenses hearing aids.
- **Geneticist/Genetic Counselor** - geneticists are physicians, and genetic counselors are health professionals, both who diagnose and treat conditions that may be caused by changes in genes. Both specialize in the care of individuals and families who may have conditions that are present at birth, including facial differences. Together, the geneticist and genetic counselor provide a medical evaluation to help you understand the cause of a given condition and the chance that other members of your family or future children may have the same condition.
- **Neurosurgeon** - a physician trained in surgical and non-surgical management of the nervous system (e.g., brain, nerves). A neurosurgeon may work closely with the plastic and reconstructive surgeon if your child requires surgery on the skull or facial bones that are close to the brain.
- **Nurse** - a health care professional who focuses on promoting and optimizing the health of individuals and families. Nurses on craniofacial teams often coordinate your child's care with other members of the team and can provide education and practical advice related to facial differences.
- **Ophthalmologist** - a physician who specializes in the medical and surgical care of the eyes. This physician can provide a full spectrum of care including routine eye exams, prescriptions for eyeglasses, diagnosis and treatment of eye disorders, and management of eye problems that may be associated with some facial differences.
- **Orthodontist** - a dentist who specializes in the diagnosis, prevention, and treatment of irregularities of the teeth and jaws. An orthodontist may use braces and retainers, among other methods, to help straighten teeth and align jaws.
- **Otolaryngologist** - a physician, sometimes called an ear, nose, and throat doctor or ENT, who specializes in the diagnosis, management, and treatment of disorders of the ear, nose, throat, and related structures of the head and neck, including the sinuses, larynx (voice box), oral cavity, and upper pharynx (mouth and throat). An otolaryngologist addresses issues such as hearing problems, ear infections, and breathing problems.
- **Pediatric Dentist (Pedodontist)** - a dentist who provides routine dental care to children. Sometimes children with facial differences may have teeth in unusual positions in the mouth. The dentist will help ensure that those teeth remain clean and healthy so that your child may be prepared for future orthodontic care.
- **Plastic and Reconstructive Surgeon** - a surgeon who has extensive training in performing operations on people with facial differences. These surgeries can include reshaping bones in the skull or face, closing cleft lips/palates, and reconstructing facial structures such as the nose or chin. The goal of these

surgeries is to improve function and appearance. At many craniofacial centers, the plastic and reconstructive surgeon leads the interdisciplinary team.

- **Program Coordinator** - the team member, often a nurse, who helps to coordinate your child's appointments with craniofacial team members. The program coordinator may also schedule appointments, tests, and procedures ordered by team members, and obtain insurance pre-authorization for those tests and procedures.
- **Prosthodontist** - a dentist who specializes in the replacement of missing teeth and the restoration of natural teeth in order to improve function and appearance.
- **Psychologist** - a professional who is trained in the study of the mind, behavior, and emotions. A psychologist works with families to help promote a smooth and healthy emotional adjustment to having a child with special needs. The psychologist can provide coping strategies which may help parents develop positive parenting skills, improve communication between family members, and foster self-esteem in their child.
- **Social Worker** - a mental health professional who helps your family identify and address the non-medical issues that may affect your child's treatment plan. These may include the emotional impact of having a child with a facial difference, financial issues, and insurance issues. The social worker provides supportive counseling to help the family discuss social and/or emotional challenges. The social worker may also connect families to appropriate resources in the community, such as support groups and networks of other families with a child with the same condition.
- **Speech and Language Pathologist** - a professional, sometimes called a speech therapist, who specializes in assessing, diagnosing, and treating disorders related to speech, language, voice, swallowing, and fluency. The discipline of speech and language pathology includes professionals who are trained in the techniques, strategies, and interventions designed to improve word pronunciation and language development.

Feel free to ask your team to refer your child to a specialist if you think that specialist's input into the treatment plan would be of benefit. Remember, you are your child's best advocate!

Organizations and references that may provide you with additional helpful information about craniofacial teams include:

Ameriface (previously AboutFace USA) P.O. Box 751112 Las Vegas, NV 89136 (888) 486-1209 www.ameriface.com	American Cleft Palate-Craniofacial Association (ACPA) 1504 Franklin Street, Suite 102 Chapel Hill, NC 27514 (919) 933-9044 www.acpa-cpf.org
Ameriface provides listings of craniofacial teams in the United States and the world.	The ACPA provides pamphlets with information about craniofacial team standards of care: Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies. Summary of Recommendations, American Cleft Palate-Craniofacial Association <i>May 1993, Rev. 2000, Rev. 2007</i> The Cleft and Craniofacial Team. Prepared by the Team Standards Committee, American Cleft Palate-Craniofacial Association <i>March 1996</i>

MAKING THE MOST OF YOUR CHILD'S HEALTH CARE APPOINTMENTS

As parents, you are a very important part of your child's craniofacial team. You and your family will have input into your child's treatment plan and you will be asked to make certain decisions on behalf of your child. In order to make the best decisions, you need to understand all of the options available to you and your child. The following suggestions are intended to prepare you to make informed decisions as you interact with your child's health care professionals.

Your child will often be seen by multiple clinicians from different specialties during a single visit at a craniofacial center. An advantage of this approach is that it prevents you from having to make multiple appointments and take your child to each health care professional's individual office. However, it can initially be overwhelming to meet with many clinicians at once. During such a visit, the health care providers will ask you and your child many questions and often talk amongst themselves. Open communication is essential for a successful partnership. It is very important that your child's doctor and other team members explain all the options to you. Do not hesitate to ask the clinicians any questions you may have.

When interacting with health care professionals, you may notice that clinicians from different fields often use different terminology. While it can be challenging at first, as you communicate more with clinicians from various fields, you will become increasingly comfortable translating between the specialties.

Tips for a successful appointment:

- All of the medical professionals who examine or treat your child should be prepared to answer your questions.
- If you do not understand what you are being told, ask to have information repeated. Sometimes medical professionals use terms or abbreviations that may be unfamiliar to you. If you ask for clarification, your health care provider will explain what he or she said in a way that is understandable to you.
- Prior to your child's appointment, think about what information you will need to make informed decisions about your child's medical condition and treatment plan. If possible, discuss this with your family and friends.
- Prior to your child's appointment, write down any questions you may have. It can help you to focus your thoughts and concerns.
- Be prepared to discuss your goals for your child. Be clear about what you want to address during this particular appointment and during future appointments.
- If possible, bring a family member or friend to your child's appointment. When receiving lots of new information it can be helpful to have a second person hear what you are told in case you miss something or are distracted.
- Before leaving a physician's office, remember to write down the names and contact information of the health care professionals and staff you encountered.
- Remember to bring your insurance cards to your child's appointment. When the office makes a copy for their records, be sure that the originals are returned to you.

Keeping a journal:

Keeping a journal of observations of your child is a helpful way to document and explain to your medical team what your child experiences on a daily basis. This is especially helpful if your child has a behavior or symptom that appears occasionally, but not during your child's appointment. Provide detailed accounts of what you observe. You may want to note the following related to your child and his or her care in your journal:

- Medication history: those your child is currently taking, including the dosage and frequency of use, any previous medications prescribed, and any side effects experienced at any time. Make sure you have the correct spelling of the medications.
- Any alternative treatments your child has been given, including vitamins, supplements, or other over the counter medications. Be very clear about any and all treatments your child has encountered.

- All observations of behaviors, symptoms, or concerns (e.g., sleep patterns, changes in behaviors, appetite).
- Notes on specific recommendations or information from particular health care providers (e.g., Dr. Jones told me my child needs a hearing test because..." or "Dr. Smith wants my child to have a swallow test because...")
- Any questions that arise. Keep the journal in a convenient place so that when you think of a question you can write it down quickly before you become distracted and forget it.
- A "to do" list regarding your child's medical care (e.g., to schedule an appointment for a hearing test, to bring a copy of your child's medical report to his or her next appointment, etc.). It's normal to forget these little details, so being able to refer to your list can be helpful.

Bring this journal with you to every appointment. Write down the date on a new page for every appointment and note what happens.

Medical history

When planning a visit to a health care professional, make sure the clinician's office has your child's medical history. If you are visiting a health care professional for the first time, you should have your child's medical history sent from your pediatrician or other referring physician. Keep copies of all reports about your child. You may obtain copies of your child's medical record upon request. The medical record contains copies of all test results as well as progress reports. In certain circumstances, it may also be necessary to obtain copies of films (e.g., MRI, CT, etc.).

During the course of your child's treatment, he or she will most likely have appointments with various medical specialists. Make sure these specialists send their reports to your child's pediatrician and to the craniofacial team. You may also request a copy of a specialist's report, which you can bring to your next appointment. This may be helpful in the event you have an appointment with a clinician who has not yet received a copy of a report.

Be sure to bring the following to your child's appointments:

- All of your insurance cards, and/or state and federal entitlement program cards.
- Your child's medical history, including addresses and phone numbers of all previous physicians.
- Your family health history.
- Your journal and a pen to write down your questions and answers to your questions.
- The "Parent Worksheet to Prepare for a Child's Medical Appointment" provided at the end of this chapter. The worksheet may help you organize the information you need for your child's appointment.

What questions should I ask?

An appointment with a physician or craniofacial team member is an opportunity to discuss any questions or concerns you may have regarding the care of your child. Do not feel that a question is "silly" or "not important." All of your questions are valid. Your health care team will want you to feel comfortable and will want you to leave your appointment with your questions answered.

Examples of questions for the craniofacial team include:

- How would you describe my child's health condition(s)?
- How often do you see this condition in other children and what can be done to treat it?
- What other health issues may my child experience?
- What medical tests should my child have?
- Do you know of another family I could speak with who has a child with the same or similar condition?
- What treatment do you recommend? What short-term treatment? What long-term treatment?
- Have you performed this treatment on other children?
- Do you have any before and after photographs of children who have received the treatment you recommend for my child?
- What complications may occur from the treatment you are recommending?

- What follow-up care may be needed?
- Will my child have any activity restrictions as a result of the recommended treatment?
- Will my child require more than one surgical procedure? If so, how many?
- What may happen if my child does not receive any treatment?
- Are there options other than surgery?

Talking to other parents can also help when preparing to meet with a physician.

Should I seek a second opinion?

Some parents find obtaining a second opinion helpful when considering major treatment decisions about their child, such as surgery. Seeking a second opinion does not mean that you do not trust your child's health care team. You want to be sure you are making the right decision. Obtaining a second opinion will reaffirm this trust. Physicians and craniofacial teams most often welcome and encourage second opinions. In fact, they may be able to give you the names and numbers of other specialists. Your team will want you to be completely comfortable with the treatment plan. In addition, your health insurance carrier may require second opinions in order to proceed with a surgical intervention. Obtaining a second medical opinion requires some effort. You will need to find a physician, obtain copies of your child's medical records, and repeat your child's medical history. Some insurance carriers do not cover second opinions, so it is important to discuss obtaining a second opinion with your insurance carrier before you do so. However, while second and even third opinions require time and resources, it may be worth the effort in order to feel comfortable and secure with the team you select for your child's care.

Being prepared for your child's appointments and keeping all medical likelihood that your child's visit is beneficial, efficient, and productive.

PARENT WORKSHEET TO PREPARE FOR A CHILD'S MEDICAL APPOINTMENT	
Child's Name: _____ Date of Birth: _____ Birth Weight: _____ Birth Height: _____ Weeks of Gestation: _____ Medical/Health Information: Current Diagnosis/Presenting Issue: _____ Current Medications and Dosage: _____ Allergies (food, medication, environmental): _____ Treatment for Allergy: _____ Parent/Guardian Information: Parent or Guardian Name: _____ Contact Number: _____ Parent or Guardian Name: _____ Contact Number: _____	Insurance Information: Primary Company: _____ Policy #: _____ Phone: _____ Secondary Company: _____ Policy #: _____ Phone: _____ History of Medical Treatments: (name and date of procedure) _____ _____ Family Observations: _____ _____ Questions for Health Care Professional _____ _____ _____ _____
Medical Team Information:	
Pediatrician: _____ Phone: _____ Doctor 1: _____ Phone: _____ Doctor 2: _____ Phone: _____ Doctor 3: _____ Phone: _____	Social Worker: _____ Phone: _____ Physical Therapist: _____ Phone: _____ Occupational Therapist: _____ Phone: _____ Speech Pathologist: _____ Phone: _____

LOOKING FOR SUPPORT

As the parent of a child with a facial difference, you are challenged with the additional role of advocate for your child so that you can access the best care and assistance available for him or her. While this may seem daunting at first, rest assured that with the right tools and support, you and your family will be able to secure the quality care your child requires and deserves.

While it is beyond the scope of this guide to list all of the programs and services that may be available in your area, the purpose of Chapters 6-11 is to provide you with a starting point for finding the resources you need to help you care for your child with a facial difference. Please note that this guide is not intended to replace information provided to you by your health care team or to provide you with medical advice.

How to look for support

We encourage you to seek the support and resources that will help your child to learn, play, meet developmental milestones, build relationships, and live a happy and productive life. One of the best resources available to you is another family with a child whose medical condition is similar to that of your child. Such families can understand what your family is experiencing and may be able to share some of their experiences and what they have learned from them. Your hospital social worker or physician may be able to connect you to another family. We list national family resources in Chapters 10 and 11 that may provide a network to other families.

Additional sources of support may be found through: medical facilities, federal and state governmental programs, community support organizations, professional and voluntary organizations, and private foundations. A listing of some of these resources is provided in Chapters 7-11.

As you embark on your search for the proper resources, keep in mind the following guidelines:

1. Choose a method of organizing information in the form of a journal, worksheet, or calendar. Divide your information into important phone numbers, a log of appointments, dated notes from these appointments, and printouts of important information. Also include the names of the people with whom you communicated and the date that you spoke. Keep a pen or pencil attached to the journal and always keep the journal in the same place so that you can find it at a moment's notice.
2. Be sure to keep copies of all medical records, test results, referrals, doctors' notes and other documents related to your child's medical history in a file or folder in one place. Make copies of all important documents. If you have health insurance, be sure to keep all insurance information in this file and make copies of your insurance cards in case the originals are misplaced.
3. Talk to your child's physician or medical team about the resources at your medical facility for your child's medical and support needs. Are there other parents with whom you can talk? Is there a social worker available to you? Is there a medical or research librarian who can help you to research your child's condition? The medical team should be able to recommend local organizations to which they have referred other families. Additional information on local organizations and family networks is in Chapters 10 and 11 of this guide.
4. Look to your local community such as your public library and governmental offices for support. Your local health department can provide you with information about disability services, Early Intervention (EI) programs, parent networks, local doctors, medical expense assistance, and other topics pertaining to your child's health and the services available in your area.

You can find information on your local health department by: a) using an Internet search engine, b) looking in your local telephone book under state or city governmental information, or c) calling or writing the U.S. Department of Health and Human Services.

The U.S. Department of Health and Human Services (HHS)

200 Independence Avenue, S.W. Washington, DC 20201

(877) 696-6775 | (202) 619-0257 | www.hhs.gov

Information is available on this site in Spanish.

5. Look for national organizations! There are many organizations that exist specifically to help you and your child. The following chapters of this resource guide include the contact information of various organizations that may help you begin your search.

CHAPTER 7

INFORMATION ABOUT DISABILITIES AND FACIAL DIFFERENCES

The term disabled means different things to different people. While you may not view your child as having a disability, there are times when it may be necessary to allow others to refer to your child as disabled in order for your child to receive appropriate services, especially when you are working with the federal and state government. The term disability does not need to be a label that limits your child, but a term you can use to help identify your child's special needs. Hope Charkins, the mother of a child who has a facial difference and the author of the book, *Children with Facial Difference*, writes: "Do not assume that a disability is an inability. When we do, we severely limit the horizons of those with chronic illnesses and disabilities, and in doing so; we limit our own horizons as well."¹

DISABILITY SERVICES - KNOW THE LAWS

It is important to know your rights and the rights of your child. If your child has a disability, he or she may have specific rights that are covered under U.S. laws. The following information cites important legislation that may affect your family.

The U.S. Department of Health and Human Services' Office for Civil Rights (OCR) website describes the Americans with Disabilities Act as follows:²

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) of 1990 provides comprehensive civil rights protection to individuals with disabilities, including children, in the areas of employment, state and local government services, public accommodations, transportation, and telecommunications.

Who Is Protected Under the ADA?

The ADA protects "*qualified individuals with disabilities*." An *individual with a disability* is a person who has a medically documented physical or mental impairment that substantially limits *major life activities*. Major life activities include functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. Under the ADA, "*a qualified individual with a disability*" is an individual who meets the essential eligibility requirements to receive services or participate in programs or activities. The ADA requires a case-by-case determination of whether a medical condition falls within their definition and guidelines. *Physical or mental impairments* can include visual, speech, and hearing impairments, developmental delays, emotional illness, and specific learning disabilities.

What is Title II of the ADA?

Title II of the ADA prohibits discrimination against individuals with disabilities in all public programs, activities, and services. Public programs include state and local governments and their departments and agencies. The OCR of the U.S. Department of Health and Human Services (HHS) has the responsibility under Title II of the ADA for state and local health care and human service agencies. The OCR protects individuals with disabilities from discrimination in the provision of benefits or services and in programs or activities on the basis of their disability.

The following organizations can provide you with more detailed information about the ADA.

Office for Civil Rights (OCR)

U. S. Department of Health and Human Services
200 Independence Avenue, S.W., Room 506-F Washington, DC 20201
(800) 368-1019 | (800) 537-7697 (TTY) | www.hhs.gov/ocr

The OCR is a part of the U.S. Department of Health and Human Services (HHS). The mission of the OCR is to ensure that people have equal access to HHS programs and services against. The OCR also works to promote the privacy of health information.

U.S. Department of Justice

950 Pennsylvania Avenue, N.W. Washington, DC 20530
(800) 514-0301 | (800) 514-0383 (TTY) | www.justice.org | www.ada.gov
Information is available on this site in Spanish.

The U.S. Department of Justice provides materials on the ADA, including the ADA statute, ADA title II and III regulations, technical assistance materials, enforcement information, and general ADA information.

¹Charkins, H. *Children with Facial Differences: A Parents' Guide*. Bethesda, MD: Woodbine House, 1996.

²<http://www.hhs.gov/ocr/ada.html>

Child Care and the ADA:

Child Care Law Center (CCLC)

221 Pine Street, 3rd Floor San Francisco, CA 94104
(415) 394-7144 | www.childcarelaw.org
Information is available on this site in Spanish.

The CCLC is a national non-profit organization that focuses on legal issues related to child care. The mission of the CCLC is to use legal tools to promote the availability of high quality and affordable child care. This organization provides a quick reference to the ADA for child care providers and can clarify when a child care program is required under the ADA to admit a child with a disability.

GENERAL DISABILITY RESOURCES

Disability services - How do I receive services?

You can begin the process of securing state disability services for your child while in the hospital after giving birth to a child with a facial difference. If your birthing center or the social worker at your hospital does not offer assistance getting these services, use the following resources to begin the process.

US Department of Labor - Disability Office

Frances Perkins Building
200 Constitution Avenue, N.W. Washington, DC 20210
(800) 772-1213 | (800) 325-0778 (TTY) | www.disabilityinfo.gov

This U.S. Department of Labor Disability Office's website provides disability-related information on topics such as "benefits, civil rights, community life, education, employment, housing, health, technology, and transportation." The organization serves not only persons with disabilities, but also their families and employers. Disabilityinfo.gov enables you to view or order a booklet that explains the benefits for which a child with a disability may be eligible. For example, the booklet describes Social Security, Supplemental Security Income (SSI), and health benefits. The website also contains a section on parent resources.

SUPPLEMENTAL SECURITY INCOME (SSI) FOR CHILDREN WITH DISABILITIES

Children with disabilities can qualify for financial support through the Social Security Income (SSI) program. This entitlement program is managed by the Social Security Administration. SSI makes monthly payments to people with low-income and limited resources who are 65 or older, blind, or disabled. A child under age 18 can also qualify if he or she meet Social Security's definition of disability for children, and if the family's income and resources fall within the eligibility limits. The amount of the SSI payment is different in each state because some states add to the federal SSI payment. Your local Social Security office can tell you more about your state's total SSI payment. If your child qualifies for SSI, the Social Security Administration will refer you to centers and programs where you can obtain health care services for your child. These services are covered under the Children with Special Health Care Needs provision of the Social Security Act and are usually managed by state health agencies. States call health care programs for children by many different names, including Children's Special Health Services, Children's Medical Services, and Handicapped Children's Program. These health care programs provide services through clinics, private offices, hospital-based outpatient and inpatient treatment centers, or community agencies.

Contact the local Social Security office in your community to learn more about SSI and to complete the application process. Your child must have a U.S. birth certificate and Social Security card to apply for this benefit. Be prepared to describe your child's medical condition and to provide the contact information of your child's physician. Once you submit an application for this benefit, the Social Security Administration will send your child's physician a medical form. This form must be completed by your child's physician and returned to the Social Security Administration in order to verify that your child's condition can be classified as disabling. A disabling condition can be temporary or life-long. The Social Security Administration will notify you once the application is processed, which typically takes about three months. If your child is rejected for the benefit, the Social Security Administration will notify you of the appeal process.

If your child is approved to receive SSI benefits, you will receive a monthly payment in the form of a check. The amount of the monthly payment will depend upon the financial information you submitted with the application. Payments will continue as long as your child is classified as being disabled. You will have to re-certify this benefit for your child periodically by submitting updated medical and financial information for review. The Social Security Administration will contact you when your child's benefit status is up for review.

Once your child has been approved to receive SSI benefits, you will be referred to your state's Medical Assistance Program (Medicaid) that will help to cover the costs of your child's medical services. Medicaid is described in more detail in Chapter 9.

You can inquire about SSI and how to apply for benefits by contacting:

Social Security Administration
Office of Public Inquiries
Windsor Park Building
6401 Security Boulevard Baltimore, MD 21235
(800) 772-1213 | (800) 325-0778 (TTY) | www.socialsecurity.gov
Information is available on this site in Spanish.

Information in Spanish on Disability Topics:

The National Dissemination Center for Children with Disabilities (NICHCY)
P.O. Box 1492 Washington, DC 20013
(800) 695-0285 (Voice and TTY) | www.nichcy.gov
Information is available on this site in Spanish.

NICHCY has created a website dedicated to connecting Spanish-speaking families to resources for their disabled child. Visit the following website for a list of publications and websites that are available in Spanish: www.nichcy.org/resources/spanishtopics

EARLY INTERVENTION SERVICES

The early years of a child's life include many important developmental milestones. Some children and families face special challenges and need extra help overcoming them. Early intervention services can help you and your family learn how to support and promote your child's development.

Early intervention services are provided by a state agency for eligible infants, toddlers, and their families. These special services are designed to identify and meet children's needs in five developmental areas:

- Physical development
- Cognitive development
- Communication
- Social or emotional development
- Adaptive development

Early intervention services address the needs of infants and toddlers who have, or are at risk of having, developmental delays as a result of their facial difference. Early intervention services are made available through a federal law known as the Individuals with Disabilities Education Act (IDEA). IDEA gives general guidelines about meeting requirements under the law. However, each state develops its own policies for implementing its early intervention programs and thus the services that are provided by these programs may vary.

Children eligible for early intervention typically range from birth to three years of age. Under IDEA, a complete evaluation of a child is necessary to decide whether the child is eligible for early intervention services. This evaluation determines if a child has, or is at risk of developing, a disability or has a special need that may affect his or her development.

Early intervention programs either focus on a child alone or on the child and the family together. Programs may operate out of centers, homes, hospitals, or a combination of these. These programs provide services that may include evaluation, treatment referrals, and direct intervention. We advise you to begin early intervention as early as possible to help your child thrive.

Where do I go for help?

There are a number of ways to locate early intervention services in your community:

- Ask your child's pediatrician for information about the early intervention system in your community.
- Contact the department of pediatrics at your local hospital.
- Contact your local health department.
- Look in your Yellow Pages telephone book.

The National Dissemination Center for Children with Disabilities (NICHCY), listed below, is an organization that provides important information about state-specific early intervention programs as well as other helpful resources.

National Dissemination Center for Children with Disabilities (NICHCY)

P.O. Box 1492 Washington, DC 20013
(800) 695-0285 | www.nichcy.org

NICHCY compiles disability-related resources in each state and creates state resource pages for particular states. The organization's handy resource sheets help you locate organizations and agencies within your state that address disability-related issues. These include state agencies that service children with disabilities, state chapters of disability organizations, parent groups, and parent training and information projects. NICHCY also provides materials on a number of topics related to parenting a child with special needs and accessing resources.

What should I say to the early intervention contact person?

When you speak with someone from an early intervention organization, explain that you are concerned about the possible effects of your child's facial difference on his or her development and say that you believe that your child may benefit from early intervention services. Your description of your child will help the representative determine which early intervention services to suggest. Write down the name of the person with whom you speak and take notes on your conversation.

Organizations that may help you locate early intervention services in your community include:

U.S. Department of Education

Office of Special Education and Rehabilitative Services (OSERS)
400 Maryland Avenue, S.W. | Washington, DC 20202
(800) 872-5327 | (800) 437-0833 (TTY) | www.ed.gov
Information is available on this site in Spanish.

The OSERS promotes the full participation in society of persons with disabilities by “ensuring equal opportunity and access to, and excellence in, education, employment and community living.” The OSERS supports programs that educate children with disabilities and programs that rehabilitate children and adults with disabilities.

The U.S. Department of Health and Human Services (HHS)

200 Independence Avenue, S.W. Washington, DC 20201
(877) 696-6775 | (202) 619-0257 | www.hhs.gov
Information is available on this site in Spanish.

HHS administers all federal programs involving health and welfare. HHS has community-based offices that can provide information on health-related issues and local services, including early intervention services.

What happens next?

Once you make contact with the early intervention system in your state, you will be assigned a service coordinator to work with you throughout the evaluation and assessment process. Service coordinators typically have a background in early childhood development and are knowledgeable about the early intervention programs and services in your state. The early intervention staff will then carry out an evaluation and assessment of your child.

What is an evaluation and assessment?

IDEA requires that your child receives a timely, comprehensive, interdisciplinary evaluation and assessment. The purpose of the evaluation and assessment is to find out the nature of your child's strengths, delays, or difficulties and determine whether your child is eligible for early intervention services.

Following your child's evaluation, you and a team of professionals will review the results of the evaluation and discuss whether your child meets eligibility criteria for early intervention services. When conducting the evaluation and assessment, team members may obtain information from the following sources that can help them identify what services your child may need:

- Doctors' reports that document your child's medical and developmental history.
- Results from your child's developmental tests and performance assessments.
- Direct observations and feedback from you and members of the interdisciplinary assessment team.
- Interviews with you and other family members or caregivers.
- Any other important observations, records, or reports about your child.

Who pays for the evaluation and assessment?

Under IDEA, evaluations and assessments are provided at no cost to parents. They are supported by state and federal funds.

My child has been found eligible for services. What happens next?

If your child is found eligible to receive early intervention services, you and the assessment team will meet to develop a written plan for providing services to your child and family. This plan is called the Individualized Family Service Plan (IFSP).

What is an individualized family service plan (IFSP)?

The IFSP is a document, written by the assessment team members with your input, that outlines the early intervention services that your child and family should receive. Team members may come from several agencies and may include medical professionals, therapists (physical, occupational, speech), child development specialists, and social workers.

The IFSP is reviewed every six months and is updated at least once a year. The IFSP must be fully explained to you and your suggestions must be considered. You must give written consent before services can start. If you do not give your consent in writing, your child will not receive services.

Each state has specific guidelines for the IFSP. Your service coordinator can explain the IFSP guidelines in your state. Your child is then referred to a community-based early intervention program. The program will assign the professionals who will work with your child to meet the goals of your child's IFSP.

What is included in early intervention services?

Depending on your child's needs, early intervention services may include:

- Assistive technology devices and services
- Audiology services (hearing impairment services)
- Family training, counseling, and home visits
- Medical services (only for diagnostic or evaluation purposes)
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination that will help ensure your child and family are receiving the services that have been identified by the IFSP
- Social work services
- Special education
- Speech and language pathology services (sometimes referred to as speech therapy)
- Transportation

Will I have to pay for any services?

Under IDEA, the following services must be provided at no cost to families:

- Assistance in locating an early intervention program in your community
- Evaluations and assessments
- Development and review of the IFSP
- Service coordination

Depending on the policies of your state, you may have to pay for certain other services. You may be

charged on a “sliding-scale,” meaning that the fees are based on family income. Some services may be covered by your health insurance or one of your state’s medical assistance programs. Early intervention programs make every effort to provide services to all infants and toddlers who need help, regardless of family income. Services can not be denied to an eligible child based on financial need. Check with the contact person in your area or state for more information.

Other resources for information about Early Intervention

Child Find
www.childfindidea.org

Child Find’s website is designed to locate, identify, and refer young children with disabilities and their families who are in need of early intervention services or preschool special education programs. Child Find screens and evaluates early intervention programs and promotes public awareness.

Kid Source Online
(408)253-0246 | www.kidsource.com

Kid Source Online explains the foundation of early intervention services and what to expect when receiving services. It also provides detailed information on stages of child development.

National Center for Hearing Assessment and Management (NCHAM)
Utah State University
2880 Old Main Hill Logan, Utah 84322
(435) 797-3584 | www.infanthearing.org

NCHAM’s goal is “to ensure that all infants and toddlers with hearing loss are identified as early as possible and are provided with timely and appropriate audiological, educational, and medical intervention.” NCHAM provides detailed information about resources that are available in each state.

National Early Childhood Technical Assistance Center (NECTAC)
517 South Greensboro Street Carrboro, NC 27510
(919) 962-2001 | (919) 843-3269 (TTY) | www.nectac.org

NECTAC explains the details of the Individuals with Disabilities Education Act (IDEA). The center provides a comprehensive online list of resources for children.

What happens after my child turns three?

When your child turns three years of age, if the early intervention program determines that he or she still requires early intervention services, the staff will make a referral to a special preschool program in your community and will assist you with this transition process. If your child continues to meet the eligibility criteria after preschool, he or she will continue to receive services through the school system. Individuals who meet the eligibility criteria may receive special education services up to the age of 21. When children progress from preschool to elementary school, parents sometimes need to strongly advocate for their children to receive special education services. Parents may find it worthwhile to seek the assistance of legal counsel when trying to negotiate this process.

There are many services provided through special education to help your child thrive in school. For example, there may be tutoring sessions, provision of a personal teacher’s aide, and/or inclusion model programs where the child receives special services within, rather than outside of, the main classroom. Special education services can vary widely from state to state and from school district to school district. It is advisable to contact your local board of education to find out what is available in your particular community. The National Early Childhood Technical Assistance Center (NECTAC), listed above, provides more detailed information about particular state services and the different parts of IDEA that regulate education services from early intervention programs through special education services.

HEALTH INSURANCE, FINANCIAL SERVICES, AND TRAVEL AND LODGING RESOURCES

Navigating health insurance policies, medical bills, and federal assistance programs can be challenging. This chapter of the Resource Guide will provide you with information on health insurance and sources of financial support, and offer you some advice about how to take full advantage of the resources available to you.

After learning that your child has a facial difference, one of your first tasks will be to determine how to balance the costs associated with your child's medical needs with your health insurance plan and your financial situation. It is not advisable to wait until your child's treatment is underway to determine how you will handle the financial impact of medical bills. We urge you to be proactive and to work on this issue as soon as you learn of your child's facial difference. There are many organizations that provide financial support to families if they need this form of assistance. However, it can take time to locate the appropriate ones and to get your child enrolled. Be sure to discuss your financial needs and concerns with your child's medical team, especially the social worker, as they may be familiar with the financial resources in your community.

The topics in this chapter of the Resource Guide have been divided into the following sections: 1.) Health Insurance, 2.) State and Federal Health Insurance Programs, 3.) Foundations and Service Organizations for Financial Assistance, and 4.) Travel and Lodging Resources.

SECTION 1 HEALTH INSURANCE

Whether you are searching for health insurance, trying to determine what is covered by your current plan, or reviewing statements, health insurance issues can be complicated. In addition to the information presented in this section, you may find the glossary of terms related to insurance in Chapter 12 to be helpful.

If you are currently searching for health insurance or have questions regarding insurance carriers you may want to explore the Health Insurance Info website.

Locating Health Insurance:

HealthInsurance.info
www.healthinsurance.info

HealthInsurance.info provides information on health-related topics, including how to locate a health insurance provider. The website offers a primer on basic health insurance principles as well as links to specific health insurance plans.

Learning about your plan:

It is essential that you understand your health insurance plan **before** your child has treatment. Always request an entire copy of your health insurance policy, which will include, but not be limited to, the benefits summary brochure. The benefits summary brochure provides an overview of what services are covered by your health insurance plan. However, the benefits summary lacks detail and will likely leave you with many unanswered questions. Read the entire policy. It will provide you with more detailed information about what is and what is not covered under your particular health insurance plan. When reviewing your health insurance policy, consider the following:

- Does the policy cover general medical care (doctor appointments, medical equipment)?
- Under the policy, are there distinctions between in-network and out-of-network providers? Are there additional costs associated with visiting out-of-network providers? If so, what are the costs?
- Does your policy cover surgery?

- Does your policy require pre-certification for admission to the hospital, surgery, and special procedures?
- Does your policy cover prescriptions?
- Does your policy cover dental and orthodontic care?
- Does your policy cover speech and hearing services?
- Does your policy cover psychological counseling?
- Does your policy require referrals? If so, for what services?
- Does your policy cover home care services, such as a visiting nurse, and medical equipment?
- Does your plan have a deductible? Be aware of any deductible amounts that you will be responsible for before your insurance plan will begin to cover medical care.
- Does your policy require you to make copayments or “copays” for office visits or other appointments? Will the copay be different for various office visits or other services? How much are the copays?
- Does your policy have a certain lifetime benefit limit for each family member? Insurance plans often have a lifetime limit on how much medical care will be covered for each covered family member.
- If you have secondary health insurance, make sure you know those benefits as well.
- If you have state-funded medical coverage, make sure that you are still registered with that program well before any surgery or procedure date.

It is important to find out from your child’s craniofacial team what specific procedures or treatments are planned for your child and to contact your health insurance carrier to find out if those services are covered.

Appealing a rejection for services:

Unfortunately, even if you plan ahead, follow the appropriate procedures, and receive pre-authorization, you may still encounter issues with your health insurance carrier. For example, your health insurance company may deny a claim or refuse to pay for a portion of a procedure. However, you have the right to appeal any decision made by your insurance company. For this reason, it is particularly important to be knowledgeable about your health insurance policy.

It is possible that your health company’s review board or medical director may decide that a particular procedure is not medically necessary or may deny coverage for certain services. In addition, your health insurance carrier may want your child to see a different physician from the one you want your child to see. In these situations, you should ask your craniofacial team to become involved and help you advocate for your child.

Educate your health insurance carrier

Your health insurance company may not understand the details of your child’s facial difference. If coverage for a particular service is denied, you may have to educate your health insurer about your child’s medical issues and the recommended treatment plan. This means that you, your child’s physician, and/or the craniofacial team will have to write letters that detail all aspects of your child’s condition, medically necessary treatment plan, and target results. If you need help writing a letter, there are a number of organizations that offer sample appeal letters. These include:

AmeriFace (previously AboutFace USA)

P.O. Box 751112 Las Vegas, NV 89136
(888) 486-1209 | www.ameriface.org

Ameriface provides advocacy and information about insurance issues, sample letters, and other resources related to facial differences.

FACES

P.O. Box 11082 Chattanooga, TN 37401
(800) 332-2373 | www.faces-cranio.org

FACES is a non-profit organization that serves children and adults with facial differences. This organization offers information and resources related to facial differences, including insurance issues.

The Sturge-Weber Foundation
P.O. Box 418 Mt. Freedom, NJ 07970
(800) 627-5482 | www.sturge-weber.org

The Sturge-Weber Foundation offers excellent information on health insurance-related issues that is relevant regardless of whether your child has Sturge-Weber Syndrome or a facial birthmark or a port wine stain. The foundation provides sample insurance forms and appeal letters.

If you find yourself still disputing a denial of benefit after an unsuccessful appeal process and if you feel that the health insurance company has violated its policy, you have the right to appeal to your State Insurance Board. The **State Insurance Board** regulates the insurance companies within your state and should be able to assist you with the next stages of your appeal process.

To locate your local State Insurance Board, check your local telephone book, contact a local government office such as the city or town hall, visit your state's website, or contact the National Association of Insurance Commissioners.

National Association of Insurance Commissioners
NAIC Executive Headquarters
2301 McGee Street, Suite 800 Kansas City, MO 64108
(816) 842-3600 | www.naic.org

The National Association of Insurance Commissioners provides information on Departments of Insurance and the insurance commissioners for each state. Departments of Insurance are typically responsible for regulating the insurance industry and enforcing many of the insurance-related laws of a particular state. Your state Department of Insurance may assist you with determining if your insurance company is following the rules and regulations stated in your policy.

Other resources you may want to contact:

U.S. Department of Health and Human Services (HHS)
200 Independence Avenue, S.W. Washington, DC 20201
(877) 696-6775 | www.hhs.gov

HHS administers all federal programs involving health and welfare. HHS has community-based offices that may provide information on health-related issues and local services.

Patient Advocate Foundation
700 Thimble Shoals Boulevard Suite 200 Newport News, VA 23606
(800) 532-5274 | www.patientadvocate.org
Information is available on this site in Spanish.

Patient Advocate Foundation is a national non-profit organization that offers assistance to families who have insurance and/or debt-related disputes with their insurer, employer, or creditor. Professional case managers and attorneys from the foundation specialize in mediation, negotiation, education, and advocacy.

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA was enacted by the U.S. Congress in 1996. One of the most important aspects of HIPAA is that it guarantees that employees who change jobs and who have had insurance coverage for at least 12 months will not have to face any restrictions (called "pre-existing condition limitations") in coverage when they enroll for health insurance with a new employer. Details about HIPAA may be obtained by contacting your local health department.

SECTION 2 STATE AND FEDERAL HEALTH INSURANCE PROGRAMS

State children's health insurance program (SCHIP):

SCHIP was created as part of the Balanced Budget Act of 1997 to address the growing problem of uninsured children. SCHIP was designed as a federal/state partnership, similar to Medicaid, with the goal of expanding health insurance coverage to children whose families earn too much money to be eligible for Medicaid, but not enough money to purchase private insurance. The program provides coverage for physician visits, hospitalizations, prescription drugs, vision, hearing, and mental health services and is available in all 50 states and the District of Columbia.

SCHIP is financed jointly by federal and state governments and is administered by the states. Within the broad federal guidelines, each state determines the design of its program, including eligibility, benefits, and payment levels for coverage.

For more details about the program in your state, contact SCHIP using the information below. Local health departments also may provide information about SCHIP.

State Children's Health Insurance Program (SCHIP)
(877) 543-7669 | www.insurekidsnow.gov
Information is available on this site in Spanish.

Medicaid:

Medicaid is a health insurance program for eligible low-income individuals and persons with disabilities in the U.S. A child may be eligible for Medicaid if he or she is a U.S. citizen or a lawfully admitted immigrant, even if his or her parents are not. A child's eligibility is based on the child's status and not the parents' status. In most states, children who receive SSI payments also qualify for Medicaid. In many states, Medicaid is initiated automatically if your child is eligible for and enrolled in SSI. In other states, you must sign up for this medical assistance program.

Medicaid is funded by the states and the federal government, but is a state-administered program. Each state sets its own guidelines for eligibility and services. When Medicaid recipients receive health care services, Medicaid will reimburse the health care provider. Depending on your state's policy, you may also be asked to pay a small portion of the cost (copayment) for some services.

Contact your local health department to find out about your particular state's guidelines for receiving Medicaid.

U.S. Health Department and Human Services (HHS)
200 Independence Avenue, S.W. Washington, DC 20201
(877) 696-6775 | (202) 619-0257 | www.hhs.gov
Information is available on this site in Spanish.

HHS is a federal government agency that may help you find your local health department. You can also check your local telephone directory.

Centers for Medicare & Medicaid Services (CMS)
7500 Securities Boulevard Baltimore, MD 21244
www.cms.hhs.gov/MedicaidGenInfo

CMS is the federal agency within the U.S. Department of Health and Human Services that is responsible for administering Medicare, Medicaid, SCHIP (State Children's Health Insurance), HIPAA (Health Insurance Portability and Accountability Act), and other health-related programs. CMS provides information about Medicaid, including eligibility criteria. The national CMS office should be able to direct you to the regional office closest to you.

The Hill Burton Act is a federal law that grants federal funds to medical facilities. As a condition of this funding, each recipient institution is required to provide a “reasonable volume” of free services to persons in the facility’s area who need care but are unable to pay. Care at facilities that receive federal funding through the Hill Burton Act is not automatically free or at reduced cost. Patients must apply at the admissions office of the facility and be found eligible to receive care that is free or at a reduced cost.

Other organizations that may provide you with information about insurance programs and entitlement/benefit programs in your state include:

Family Voices, Inc.
2340 Alamo SE, Suite 102 Albuquerque, NM 87106
(888) 835-5669 | (505) 872-4774
www.familyvoices.org

Family Voices is a national grassroots organization with offices in each state that provides information, education, and resources on topics relevant to the care of children with disabilities or chronic conditions. The mission of the organization is to promote and improve family-centered health care for children with disabilities. Through Family Voices, you may access a network in which information is shared between families, professional partners, youth leaders, and policymakers.

Government Benefits
(800) 333-4636 | GovBenefits.gov

The Government Benefits website provides a free and confidential web-based screening tool to determine eligibility for government programs. The Government Benefits website provides individuals with a list of programs for which they may be eligible and provides information on how to apply for those programs. Government Benefits does not offer assistance for completing applications to enroll in benefit programs and does not guarantee eligibility for specific programs. It is solely a web-based resource.

Health Insurance Association of America
601 Pennsylvania Avenue, N.W., Suite 500 Washington, DC 20004
(800) 828-0111 | www.hiaa.org

Health Insurance Association of America represents the insurance industry on legislative and policy affairs. It provides individuals with information on disability income, health, and general insurance topics.

SECTION 3

FOUNDATIONS AND SERVICE ORGANIZATIONS FOR FINANCIAL ASSISTANCE

Community-based foundations and service organizations may provide financial assistance for medical and related non-medical expenses. Each organization has its own policies for determining eligibility for funds. If you request financial assistance from an organization, it is important to be specific about why you are requesting the funds and for how long you anticipate needing the support.

Children's Craniofacial Association (CCA)
13140 Coit Road, Suite 307 Dallas, TX 75240
(800) 535-3643 | www.ccakids.com

CCA is a non-profit organization “dedicated to improving the quality of life for people with facial differences and their families.” CCA has a financial assistance program that provides funds for food, travel, and lodging for needy families who must travel to receive medical care. CCA also helps families locate discounted hotel rates and donated airfare.

Forward Face
317 East 34th Street, Suite 901A New York, NY 10016
(800) 393-3223 | (212) 684-5860 | www.forwardface.org

Forward Face is a non-profit organization whose mission is “to help children and their families find immediate support to manage the medical and social effects of facial differences.” The organization is devoted to strengthening families of children with facial differences. Forward Face is involved in education and advocacy activities as well as efforts to raise public awareness about facial differences. The organization offers a wide range of services to families, including a Family Assistance Fund to help families in need cover certain non-medical expenses.

World Craniofacial Foundation (WCF)
P.O. Box 515838 Dallas, Texas 75251
(800) 533-3215 | (972) 566-6669 | www.worldcf.org

The mission of the WCF is “to give help, hope, and healing to people with craniofacial abnormalities and their families.” The WCF awards financial aid grants to eligible families to assist with secondary costs of care for facial differences. Such grants may be used for food, travel, and lodging expenses associated with physician appointments, surgeries, and rehabilitation services.

SECTION 4 TRAVEL AND LODGING RESOURCES

Travel:

If you have to travel by air to a craniofacial center for your child's care and the cost of airfare is unaffordable for your family, contact the organizations below to try to obtain assistance.	
Air Charity Network National Headquarters 4300 Westgrove Drive Addison, TX 75001 (888) 486-1209 www.ameriface.com	Mercy Medical Airlift 4620 Haygood Road, Suite 1 Virginia Beach, VA 23455 (800) 296-1217 (757) 318-9174 www.mercymedical.org
Air Charity Network is a collaborative of multiple independent volunteer pilot organizations. The volunteer pilot organizations in the Air Charity Network provide free air transportation to those in need to health care facilities in the U.S. Member organizations include Airlift Hope, Angel Flight, and Mercy Flight Southeast.	Mercy Medical Airlift coordinates free airline tickets for long-distance trips for medical care for those in need. The organization also provides resources for volunteer pilot programs, including air ambulance service.
American Airlines Miles for Kids Program (800) 882-8880 www.aa.com	Miracle Flights for Kids 2764 N. Green Valley Parkway, Suite 115 Green Valley, NV 89014 (800) 359-1217 (702) 261-0494 www.miracleflights.org
The American Airlines Miles for Kids Program allows American Advantage members to donate their unused miles to help kids in need. These miles provide transportation for children from needy families who require long distance travel to receive medical care.	Miracle Flights for Kids is a national non-profit organization that provides free flights to ill children whose families are in financial need to enable them to access specialized medical care and second opinions.
Angel Flight, Inc. 1515 East 71st, Suite #312 Tulsa, OK 74136 (918) 749-8992 www.angelflight.com	National Patient Travel Center (NPTC) 4620 Haygood Road, Suite 1 Virginia Beach, VA 23455 (800) 296- 1217 www.patienttravel.org
Angel Flight arranges free air transportation for medical related purposes for individuals in need.	NPTC works "to ensure that no financially-needy patient is denied access to distant specialized medical evaluation, diagnosis or treatment because of a lack of a means of long-distance medical air transportation." The organization helps patients access charitable medical air transportation services in the U.S. and administers patient airline ticket programs.

Lodging:

If you are traveling for a consultation or treatment for your child, ask the craniofacial team if there are any local accommodations for families in the area. Some treatment centers have apartments or residence halls that are reserved specifically for visiting patients and families. Some treatment centers have relationships with local hotels that provide rooms at a reduced rate. If your child's treatment center does not have recommendations for affordable lodging, contact the national headquarters of the local hotel where you would like to stay, explain your situation, and inquire about securing a reduced rate. The hotel may require documentation for the reason of your visit, such as a letter from your child's physician.

National organizations that provide accommodations for short-term stays:

Ronald McDonald House Charities (RMDHC)
One Kroc Drive Oak Brook, IL 60523
(630) 623-7048 | www.rmhc.com

RMDHC provide "a home away from home for families of seriously ill children receiving treatment at near by hospitals." A Ronald McDonald House is maintained in most major cities in which there are facilities

that provide medical treatment to children. In return for staying at a Ronald McDonald House, RMDHC asks families to make a donation of up to \$35 per day, depending on the House. Contact the national RMDHC office or visits the organization's website to learn more about the services in your area.

The National Association of Hospital Hospitality Houses (NAHHH)

**44 Merrimon Avenue, 1st Floor Asheville, NC 28801
(800) 542-9730 | (828) 253-1188 | www.nahhh.org**

NAHHH is an association of more than 150 non-profit organizations located throughout the U.S. that provide family-centered lodging and support services to patients and their families facing medical emergencies. The facilities in the network offer home-like environments for people who must travel to receive outpatient medical care or to be with a patient.

Fisher House Foundation, Inc.

**1401 Rockville Pike, Suite 600
Rockville, MD 20852
(888) 294-8562 | (301) 294-8560 | www.fisherhouse.org**

Fisher House Foundation is a housing support organization for families in the U.S. military. Fisher houses are located on the grounds of major military and Veterans Affairs (VA) medical centers. These homes enable military families to be close to a family member who is hospitalized for medical care.

FACIAL DIFFERENCES SUPPORT ORGANIZATIONS

This chapter provides an overview of organizations that offer information and services related to the care of a child with a facial difference. Even organizations aimed at helping a population with a specific condition (e.g., Crouzon's Syndrome) have general information that may be useful to parents of a child with a facial difference. It may be of benefit to explore all of the organizations listed.

Support Organizations, Networks, and Resources for Families affected by Facial Differences:

AboutFace International

123 Edward Street, Suite 1003 Toronto, ON Canada 1E2
(800) 665-3223 | www.aboutfaceinternational.org
Information is available in French.

AboutFace International provides information on topics related to facial differences, including advocacy and psychosocial peer support.

Ameriface (previously AboutFace USA)

P.O. Box 751112 Las Vegas, NV 89136
(888) 486-1209 | www.ameriface.org

Ameriface provides a variety of resources for families of children with facial differences, including recommendations for craniofacial teams, educational materials, networking opportunities for families, a toll-free support hotline, a newborn outreach program, and information on feeding and nutrition, travel and accommodations, and insurance and advocacy.

American Cleft Palate-Craniofacial Association (ACPA)

1504 East Franklin Street, Suite 102 Chapel Hill, NC 27514
(800) 242-5338 | (919) 933-9044 | www.acpa-cpf.org

ACPA is “an international non-profit medical society of health care professionals who treat and/or perform research on birth defects of the head and face.” The goal of the members of ACPA is to provide optimal care for persons with facial differences and their families. The organization has advocated for a standard of care for treating patients with facial differences and has developed guidelines for care, which are outlined on the ACPA website.

Changing Faces

The Squire Center
33-37 University Street London WC1E 6JN
(001) 0845 4500 275 | www.changingfaces.org.uk

Changing Faces, based in Great Britain, is a non-profit organization that complements medical and surgical interventions by addressing the psychological and social challenges posed by facial differences. This organization has a large list of resource materials related to the emotional impact of a facial difference that can be downloaded or ordered online. These materials include self-help guides for adults, children, and families.

Children's Craniofacial Association (CCA)

13140 Coit Road, Suite 517 Dallas, TX 75240
(800) 535-3643 | www.ccakids.com

CCA is a non-profit organization that provides support and information to help address “medical, financial, psychosocial, emotional, and educational concerns” related to facial differences. The organization offers detailed information about specific conditions, treatment centers, and family networking, as well as links to other web-based resources.

Cleft Advocate

P.O. Box 751112 Las Vegas, NV 89136
(888) 486-1209 | www.cleftadvocate.org
Information is available on this site in Spanish.

Cleft Advocate, a program of Ameriface, aims to educate and encourage families affected by facial differences by providing educational opportunities, support networks, information about specific conditions, and links to online resources.

The Cleft Palate Foundation

1504 East Franklin Street, Suite 102 Chapel Hill, NC 27514
(919) 933-9044 | CLEFTLINE (800) 24-CLEFT | www.cleftline.org
Information is available on this site in Spanish.

The Cleft Palate Foundation is a non-profit organization that is the public service part of the American Cleft Palate-Craniofacial Association (ACPA). The Cleft Palate Foundation provides many resources, including state-specific resources, for patients and families affected by facial differences. The foundation also runs CLEFTLINE, a toll-free hotline that provides information about clefts and other facial differences.

Craniofacial Foundation of America

975 East 3rd Street, Box 269 Chattanooga, TN 37403
(800) 418-3223 | (423) 778-9192 | www.craniofacialcenter.com

The Craniofacial Foundation of America offers many services for individuals and families affected by facial differences. The organization provides financial assistance for eligible patients for non-medical expenses, such as the costs associated with traveling to the Tennessee Craniofacial Center. The Craniofacial Foundation of America also offers education and support services to the public.

Craniokids

www.craniokids.org

The goal of Craniokids is to provide a forum where families can seek and provide emotional support, share experiences, and learn about craniosynostosis. Craniokids is a web-based resource that provides family networking, support, and maintains a buddy list of families who have children with craniosynostosis.

CranioSupport.Information

www.craniosupport.info

CranioSupport.Information is a web-based resource dedicated to helping families find support and information about the different types of craniosynostosis.

Crouzon Support Network

P.O. Box 751112 Las Vegas, NV 89136
(888) 486-1209 | www.crouzon.org

The Crouzon Support Network, a part of Ameriface, provides information and support to families affected by Crouzon Syndrome and other facial differences. The organization provides resources on a variety of topics, including psychosocial issues, advocacy, and financial assistance, as well as links to other organizations that assist with insurance issues.

FACES: The National Craniofacial Association

P.O. Box 11082 Chattanooga, TN 37401
(800) 332-2373 | www.faces-cranio.org

FACES is a non-profit organization that serves children and adults with facial differences. The organization offers information and support, provides financial assistance for patient travel, and works to raise public awareness. FACES also provides links to a number of resources.

The Foundation for Faces of Children

258 Harvard Street, Suite 3 Brookline, MA 02446
(617) 355-8299 | www.facesofchildren.org

The Foundation for Faces of Children is a non-profit organization that focuses on education, training, family support systems, and the dissemination of accurate and timely information, including information about common facial differences. The organization offers a free educational video, Understanding Cleft Lip & Palate, a Guide for New Parents, in both English and Spanish.

Foundation for Nager and Miller Syndromes (FNMS)

13210 SE 342nd Street Auburn, Washington 98092
(800) 507-3667 | www.fnms.net

FNMS is an international support group dedicated to helping those affected by Nager and Miller Syndromes.

Forward Face

317 E. 34th Street, Suite 901A New York, NY 10016
(800) 393-3223 | (212) 684-5860
www.forewardface.org

Forward Face is a non-profit organization started in 1978 by parents of children with facial differences, whose mission is “to help children and their families find immediate support to manage the medical and social effects of facial differences.” The organization is involved in education and advocacy activities to raise public awareness about facial differences. Forward Face also provides psychosocial support through family networking and family gatherings, as well as financial support through a Family Relief Fund to help families in need cover certain non-medical expenses.

Freeman-Sheldon Syndrome Parent Support Group

509 Northmont Way Salt Lake City, Utah 98103
(801) 364-7060 | www.fspsg.org

Freeman-Sheldon Syndrome Parent Support Group is a parent-run organization that helps to educate and connect parents of children affected by Freeman-Sheldon syndrome. The organization’s website provides links to a number of resources.

Friendly Faces

www.friendlyfaces.org

Friendly Faces is a web-based resource, started by a parent of children with facial differences. The Friendly Faces website provides information and networking resources to families of children with facial differences. The website also offers a list of links to other resources and organizations.

Goldenhar Syndrome Support Network
P.O. Box 751112 Las Vegas, NV 89136
(888) 486-1209 | www.goldenharsyndrome.org

The Goldenhar Syndrome Support Network, a program of Ameriface, provides information related to Goldenhar Syndrome, including recommendations for craniofacial teams, educational materials, emotional support resources for families, and a state-by-state resource directory.

Jorge Posada Foundation
P.O. Box 20541 New York, NY 10021
646-264-2764 | www.jorgeposada.com/foundation/

The Jorge Posada Foundation aims to help families in need who have children with craniosynostosis. The foundation runs a family network through their Mentors Program, where volunteers who have experienced craniosynostosis in their family are partnered with families looking for support. The Jorge Posada foundation also offers financial assistance to help with the costs of surgeries performed in its partner medical centers, promotes awareness of craniosynostosis, and supports research.

Let's Face It
University of Michigan School of Dentistry/Dentistry Library
1011 North University Ann Arbor, MI 48109
www.dent.umich.edu/faceit

Let's Face It is a non-profit organization whose mission is "to advance knowledge about, by, and for people with facial differences and to promote their full and equal participation in society." The Let's Face It website provides a wide range of information and reading lists about facial differences, treatment options, and related topics.

Moebius Syndrome Foundation
c/o Vicki McCarrell
P.O. Box 147 Pilot Grove, MO 65276
(660) 834-3406 | www.ciaccess.com/moebius

Moebius Syndrome Foundation is a non-profit organization started by parents of children with the syndrome. The foundation's website provides detailed information about Moebius Syndrome as well as a list of support organizations available to families.

National Institute of Dental and Craniofacial Research (NIDCR)
National Institutes of Health
Bethesda, MD 20892
(301) 496-426 | www.nidcr.nih.gov
Information is available on this site in Spanish

NIDCR, part of the National Institutes of Health, aims "to improve oral, dental, and craniofacial health through research, research training, and the dissemination of health information." The NIDCR website also provides information about their current research studies.

National Organization for Rare Disorders (NORD)
55 Kenosia Avenue
P.O. Box 1968 Danbury, CT 06813
(203) 744-0100 | (800) 999-6673 (voice mail only)
www.rarediseases.org

NORD is a national federation of organizations serving people with rare disorders. The organization provides reports and information on various conditions including facial differences. NORD offers a number of family programs including a networking program and a resource guide for purchase.

National Organization of Vascular Anomalies (NOVA)

P.O. Box 0358 Findlay, OH 45840

www.novanews.org

Information is available on this site in French, Italian, and Spanish.

NOVA is a web-based, non-profit organization that provides assistance and support to individuals affected by hemangiomas and vascular malformations. The organization provides education, opportunities to network with other families, patient advocacy and support, family conferences, and physician referrals.

Operation Smile

6435 Tidewater Drive Norfolk, VA 23509

(888) 677-6453 | www.operationsmile.org

Operation Smile initially provided plastic and reconstructive surgery only to children in developing countries, but currently provides treatment to underprivileged children in the U.S. The organization offers a network of resources to assist families that includes referral websites, a physician resource list, and a list of related facial differences resources.

Pierre Robin Network

3604 Biscayne Quincy, IL 62305

www.pierreroobin.org

The Pierre Robin Network offers detailed resources and references for families affected by Pierre Robin Sequence, as well as information on related conditions, such as Beckwith-Wiedemann and Stickler Syndrome. The resource list provides information about feeding and speech issues, dental issues, and general support organizations. This organization is solely web-based.

Romberg's Syndrome (Parry Romberg Foundation)

52614 14th Street Windsor, CO 80550

www.parryrombergfoundation.org

The Parry Romberg Foundation provides information about Romberg's Syndrome, raises public awareness, supports research, and offers a list of resources. This organization is web-based but can be contacted via e-mail.

Stickler Involved People (SIP)

15 Angelina Drive Augusta, KS 67010

(316) 775-2993 | www.sticklers.org

SIP provides information about Stickler Syndrome, networking opportunities, psychosocial support, and other resources. Call or visit the SIP website to learn about books and DVDs about Stickler Syndrome.

Sturge-Weber Foundation

P.O. Box 418 Mount Freedom, NJ 07970

(800) 627-5482 | www.sturge-weber.com

The Sturge Weber Foundation aims to address families' questions about port wine stains and Klippel-Trenaunay. The foundation provides educational materials and information, as well as family matching for networking and resource connections.

TMJ (Temporomandibular Joint and Muscle Disorders) Association, Ltd.

P.O. Box 26770 Milwaukee, WI 53226

(262) 432-0350 | www.tmj.org

TMJ Association is committed to increasing awareness of TMJ, while providing support and education to the TMJ community. The association offers a collection of abstracts, conference reports, web site links, and information about support affiliates.

Treacher Collins Connection
P.O. Box 156 Boston, MA 02131
(704) 545-1921 | www.tcconnection.org

Treacher Collins Connection provides medical and networking resources to connect, educate, and support people with Treacher Collins Syndrome.

Vascular Birthmark Foundation (VBF)
P.O. Box 106 Latham, NY 12110
(877) 823-4646 | www.birthmark.org

VBF is an international non-profit organization that connects families affected by a vascular birthmark to medical professionals for evaluation or treatment. The foundation also offers educational and support resources to families.

Wide Smiles
P.O. Box 5153 Stockton, CA 95205
(209) 942-2812 | www.widesmiles.org

Wide Smiles offers support, information, and networking opportunities for families coping with the challenges associated with having a child with a facial difference. The organization provides information on a wide range of topics including insurance, speaking to children about their facial differences, and suggested reading for adults and children.

World Craniofacial Foundation (WCF)
P.O. Box 515838
Dallas, Texas 75251
(800) 533-3215 | (972) 566-6669 | www.worldcf.org

WCF provides financial aid grants to eligible families to assist with the secondary costs of treatment for facial differences. The foundation also helps families to network and makes referrals to community resources.

ADDITIONAL RESOURCES

The additional topics in this chapter are divided into the following sections: 1.) advocacy and legal assistance, 2.) genetic resources, 3.) parenting networks and support resources, 4.) speech, language, and hearing resources, and 5.) vision impairment resources. The organizations listed can serve as a starting point should you wish to explore the topics further.

SECTION 1 ADVOCACY AND LEGAL ASSISTANCE

Association of Maternal and Child Health Programs (AMCHP)
1220 19th Street, N.W., Suite 801 Washington, DC 20036
(202) 775-0436 | www.amchp.org

AMCHP is a non-profit organization that supports state maternal, child, and family health programs. The association has a strong advocacy division, which will work with you to obtain quality medical treatment for your child. AMCHP's website also includes information on and web links to specific maternal and child health topics.

Cleft Advocate
P.O. Box 751112 Las Vegas, NV 89136
(702) 769-9264 | www.cleftadvocate.com

Cleft Advocate provides a wide range of services for families who have children with facial differences. The website includes insurance and advocacy information.

Families USA
1201 New York Avenue, N.W., Suite 1100 Washington, DC 20005
(202) 628-3030 | www.familiesusa.org

Families USA is a non-profit organization that works "to promote high-quality, affordable health care for all Americans." The organization offers a state-by-state guide to managed care issues and policies and provides an extensive list of other advocacy organizations.

Family Voices
2340 Alamo SE, Suite 102 Albuquerque, NM 87106
(888) 835-5669 | (505) 872-4774 | www.familyvoices.org
Information is available on this site in Spanish.

Family Voices is a national coalition of family and professional advocates for children with special needs. This organization provides a network of state coordinators and publications on insurance advocacy.

Genetic Alliance
4301 Connecticut Avenue, N.W., Suite 404 Washington, DC 20008
(800) 232-4363 | (202) 966-5557
www.geneticalliance.org

Genetic Alliance offers resources for families seeking information about genetic issues and provides information about genetics-related advocacy, community organizations, and government offices.

National Health Law Program
1101 14th Street, N.W., Suite 405 Washington, DC 20005
(202) 289-7661 | www.healthlaw.org

National Health Law Program provides extensive information on health care laws affecting families whose children have special health care needs.

New England Serve
101 Tremont Street, Suite 812 Boston, MA 02108
(617) 574-9493 | www.neserve.org

New England Serve provides information on legal and financial issues for families with children with special health care needs. Visit the website or call to receive the organization's publication "Paying the Bills: Tips for Families on Financing Health Care for Children with Special Needs."

National Organization for Rare Disorders (NORD)
55 Kenosia Avenue
P.O. Box 1968 Danbury, CT 06813
(203) 744-0100 | (800) 999-6673 (voice mail only) | www.rarediseases.org

NORD is a national federation of organizations serving people with rare disorders. Reports on hundreds of conditions are available. NORD also supports families who need assistance advocating for services for proper treatment or medical coverage through private or governmental insurance programs.

Patient Advocate Foundation
700 Thimble Shoals Boulevard, Suite 200 Newport News, VA 23606
(800) 532-5274 | www.patientadvocate.org

Patient Advocate Foundation is a non-profit organization that serves as an intermediary between patients, insurers, employers, and creditors to resolve insurance issues.

SECTION 2 GENETIC RESOURCES

Genetic Alliance

4301 Connecticut Avenue, N.W., Suite 404 Washington, DC 20008
(800) 232-4363 | (202) 966-5557 | www.geneticalliance.org

Genetic Alliance offers comprehensive resources for families seeking information about genetic issues, including a basic guide to understanding genetics and disease-specific information. In addition, the organization provides information about genetics-related advocacy, community organizations, and government offices.

Genetic and Rare Diseases Information Center

P.O. Box 8126 Gaithersburg, MD 20898
(888) 205-2311 | (888) 205-3223 TTY | www.genome.gov
Information is available on this site in Spanish.

The Genetic and Rare Diseases Information Center has information specialists available to answer questions in English and Spanish from patients and their families, health care professionals, and researchers.

Genetics Home Reference

National Library of Medicine
8600 Rockville Pike Bethesda, MD 20894
(888) 346-3656 | (888) 735-2258 (TTY) | www.ghr.nlm.nih.gov

Genetics Home Reference is the website for the National Library of Medicine that provides the public with information about genetic conditions and the genes or chromosomes related to those conditions. In addition, Genetics Home Reference provides a handbook entitled, “Help Me Understand Genetics Handbook,” and a general glossary of genetic and medical terms. The website is developed by staff that includes board-certified medical geneticists, biologists, and information specialists. The content is reviewed regularly to ensure that it is accurate and up-to-date. The website is a starting point for persons interested in learning about human genetics and inherited disorders.

The Office of Rare Diseases (ORD)

National Institutes of Health (NIH)
6100 Executive Boulevard Room 3B01, MSC 7518 Bethesda, Maryland 20892
(301) 402-4336 | <http://rarediseases.info.nih.gov/>

ORD is a government organization that “coordinates research and information on rare diseases at the NIH and for the rare disease community.”

SECTION 3 PARENTING NETWORKS AND SUPPORT RESOURCES

American Self-Help Group Clearinghouse (973) 326-6789 | www.selfhelpgroups.org

American Self-Help Group Clearinghouse organizes information so that it is accessible to the public. This clearinghouse is a web-based organization that contains a database of over 1,000 national and international self-help groups.

Exceptional Parent EP Global Communications, Inc. 416 Main Street Johnstown, PA 15901 (800) 372-3861 | (814) 361-3860 | www.eparent.com

Exceptional Parent's website provides detailed information about parenting a child with special health care needs. Exceptional Parent also publishes a magazine that contains many useful resources. To subscribe to the magazine please visit the website or call for more information.

Maternal and Child Health Library 2115 Wisconsin Avenue, N.W., Suite 601 Washington, DC 20007 (202) 784-9770 | www.mchlibrary.info

The Maternal and Child Health Library website offers links to a library of information related to maternal and child health issues. It provides bibliographies, guides to selected resources, and organization lists.

MUMS: National Parent to Parent Network 150 Custer Court Green Bay, Wisconsin 54301 (877)336-5333 | (920) 336-5333 | www.netnet.net/mums

MUMS is a national organization whose purpose is to connect parents or care providers of children with disabilities, chromosomal abnormalities, or health conditions to other parents whose children have the same or similar conditions.

Parent to Parent USA www.p2pusa.org

Parent to Parent USA is a national non-profit organization that promotes access to quality parent-to-parent support. The Parent to Parent website lists organizations with parent-to-parent support programs. Such programs match parents of children with special needs who are seeking support from a trained and experienced "support parent." Contact the website for contact information for a program in your state.

Parenthub 1900 Fort Ward Hill Road Bainbridge Island, WA 98110 (206) 855-0597 | www.parenthub.com

Parenthub provides comprehensive information and resources about a wide range of issues related to parenting and family life. The Parenthub website resources available on the Internet.

SECTION 4 SPEECH, LANGUAGE, AND HEARING RESOURCES

American Society for Deaf Children
3820 Hartzdale Drive Camp Hill, PA 17011
(866) 895-4206 | (717) 703-4206 | www.deafchildren.org

The American Society for Deaf Children supports and educates families of deaf and hard-of-hearing children and advocates for high quality programs and services. The organization provides a listing of related resources, articles for parents, and links to other related organizations.

Children's Speech and Communication Resources
www.childrensdisabilities.info

Children's Speech and Communication Resources offers a web-based information site containing links to many resources regarding hearing, speech, and communication issues.

Hearing Loss Association of America (HLAA)
7910 Woodmont Ave, Suite 1200 Bethesda, MD 20814
(301) 657-2248 | (301) 657 2249 TTY | www.shhh.org

The website of the HLAA provides information on resources, education, advocacy, and support.

The Hearing Impaired Kids Endowment (HIKE) Fund, Inc.
10115 Cherryhill Place Spring Hill, FL 34608-7116
(352) 688-2579 | www.thehikefund.org

HIKE provides grants for eligible children with hearing loss to help improve their communication skills. These funds support devices such as converters for television, tactile units, FM units used for amplification by plugging in a hearing aid, and computers. The organization also promotes public awareness about hearing impairments.

National Center for Hearing Assessment and Management (NCHAM)
Utah State University
2880 Old Main Hill Logan, UT 84322
(435) 797-3584 | www.infanthearing.org

NCHAM aims “to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.” The center profiles individual state programs and provides information about other resources available to assist families.

SECTION 5 VISION IMPAIRMENT RESOURCES

American Foundation for the Blind

11 Penn Plaza, Suite 300 New York, NY 10001
(800) 232-5463 | (212) 502-7600 | www.afb.org
Information is available on this site in Spanish.

American Foundation for the Blind is a national non-profit organization that provides technical knowledge to professionals who provide services to individuals with vision impairment. The organization also promotes independence among adults and children with vision impairment by providing them and their families with resources and links to other websites.

Lighthouse International

111 E. 59th Street New York, NY 10022
(800) 809-0500 | (212) 821-9200 | www.lighthouse.org

Lighthouse International is a non-profit organization whose mission is to preserve vision and to help individuals “overcome the challenges of vision loss” through clinical services, education, research, and advocacy. The organization offers early intervention services that help infants born with vision loss reach important developmental milestones.

GLOSSARY OF TERMS

SECTION 1
TERMS RELATED TO FACIAL DIFFERENCES**-A-**

adenoids: lymphatic tissue in the back of the throat.

airway: the path that air takes to enter the lungs.

alveolar bone: the bony structure in the gums of the mouth that supports the teeth.

alveolar bone graft: the surgical addition of bone to the alveolar bone.

amblyopia: diminished vision in one or both eyes because of lack of use.

anesthesia: medication administered to provide pain relief and/or induce and maintain a drug-induced state of unconsciousness during surgery or a procedure.

anomaly: a change or deviation from what is considered typical.

apnea: cessation of air flow for longer than ten seconds before a person resumes breathing.

apnea monitor: a device that is attached to electrodes on the body and makes a noise whenever respirations do not occur in a normal pattern.

articulation: the ability to move and control the lips, tongue, jaw, and palate to produce the sounds of a language.

aspiration: liquid or food entering into the lungs.

assessment: process to determine a child's strengths and weaknesses. Includes testing and observations performed by a team of professionals. Assessment is interchangeable with the term evaluation.

asymmetry: both sides are not equally affected, such as one side of the face is different from the other side.

atresia: closing or absence of a normal body opening, such as an ear canal.

audiogram: electrical study of hearing plotted visually on a graph.

aural: hearing.

aural atresia: the lack of an ear canal.

-B-

bilateral: related to both sides.

bone distraction: surgical bone lengthening techniques also known as distraction osteogenesis.

brachydactyly: short fingers.

-C-

cephalogram: an X-ray of the face that shows a full profile and that is used to evaluate bony structures of the face and evaluate the effects of orthodontic treatments.

choanal atresia: narrowing of the closure above the soft palate between the nose and the throat that can obstruct breathing.

chromosome: a threadlike string of genes.

cleft: a split in an anatomic structure, such as a cleft lip or cleft palate.

columella: the central lower portion of the nose that divides the nostrils into right and left.

conductive hearing loss: hearing impairment that originates in the outer or middle ear as the result of blockage in the sound passageway.

congenital: a condition existing at, and usually before, birth.

craniofacial: pertaining to the head and face.

craniosynostosis: premature closing of the seams between the bones of the skull.

crossbite: a dental condition in which the upper teeth and lower teeth do not line up correctly from side to side.

CT or CAT scan (computerized tomography) scan: diagnostic procedure in which a computerized machine takes cross-sectional X-ray pictures of the body.

-D-

deformational plagiocephaly: refers to the lopsided head shape, typically with flattening in one area caused by external force or pressure.

dental arch: the curved structure formed by the teeth in their normal position.

distraction osteogenesis: a technique that uses a small metal device to slowly lengthen one or more bones without requiring a bone graft. Often used to lengthen the mandible (lower jaw) and mid-face bones.

-E-

eardrum: membrane in the ear that vibrates and transmits sound to the inner ear. Also known as the tympanic membrane.

early intervention: the specialized way of interacting with infants and toddlers to minimize the possible effects of health conditions on early development.

echocardiogram: an ultrasound picture of the heart showing its structures, including the inner chambers.

endoscopy: used to view the interior of the human body. Commonly used to view the throat or stomach.

ENT: abbreviation for ear, nose, and throat. An ENT doctor, or otolaryngologist, is a physician who specializes in the diagnosis, management, and treatment of disorders of the ear, nose, throat, and related structures of the head and neck.

eustachian tube: the air duct that connects the back of the throat with the middle ear. The eustachian tube usually is closed at one end, opens with yawning and swallowing, and allows ventilation of the middle ear cavity and equalization of pressure on the two sides of the eardrum.

exorbitism: bulging of the eye because the bony cavity around the eye (orbit) is too small and shallow.

expressive language: communication of one's ideas, desires, or intentions to others usually through

speech or printed words.

extubation: removal of the breathing tube from the nose or mouth that was used during general anesthesia.

-F-

facial tags: tags of skin in front of the ear. Also called preauricular tags.

family-centered care: a way to provide health care to patients that includes the whole family as partners with the health care team. This care also recognizes the importance of extended families, communities, and friendships.

fine motor: relating to the use of the small muscles of the body.

fistula: an abnormal connection or passageway between two epithelium-lined organs or vessels that normally do not connect. May refer to a hole in the palate, which allows a communication between the nasal and oral cavities.

fronto-orbital advancement: an operation in the front of the skull and upper eyes to expand and advance (bring forward) these structures.

-G-

gastrostomy tube (G-tube): a feeding tube that is inserted through an incision in the abdomen directly into the stomach.

gene: a unit of inheritance that serves as the blueprint or code for our development. Genes determine characteristics such as hair color and stature.

genetics: the science of heredity (how things pass from one generation to the next).

genioplasty: a surgical procedure to alter the position or appearance of the chin.

graft: procedure of transferring bone and/or tissue from one body site to another.

gross motor: relating to the use of the large muscles of the body.

-H-

Haberman feeder: a special feeding bottle and nipple designed for babies who have a cleft palate that is sometimes used for babies with other facial differences.

hard palate: the front part of the roof of the mouth containing bone covered by pink tissue (mucosa).

head orthosis helmet: a helmet that improves the shape of a baby's skull by taking advantage of rapid infant head growth.

heredity: genetically derived characteristics, abilities, and potentialities.

hydrocephaly: buildup of fluid in the cranial cavity.

hypernasality: a lack of normal nasal resonance during speech.

hypoplasia: underdevelopment of a structure.

-I-

inner ear: contains the cochlea, auditory nerve, and vestibular canals.

intracranial pressure: pressure on the brain.

intubation: placement of a breathing tube into the nose or throat when using general anesthesia.

interdisciplinary team: group of different health professionals who work together to provide a coordinated plan of care.

-L-

LeFort surgical procedure: the name of the operation used to reshape the upper jaw area.

LeFort I maxillary advancement: a procedure to move the upper jaw forward to a better position.

LeFort III midface advancement: a procedure used to move the middle and upper portion of the face forward.

-M-

macroglossia: excessively large tongue.

malocclusion: the wrong position of the two jaws resulting in a faulty meeting of the bite.

mandible: the lower jaw.

maxilla: the upper jaw.

mental health professional: a general term for a professional who is trained in understanding human behavior, emotions, and how the mind works. This professional can be a psychologist, counselor, social worker, or psychiatrist.

micrognathia: underdevelopment of the lower jaw.

microtia: abnormally small or malformed portion of the outer ear.

middle ear: the portion of the ear behind the eardrum that contains three small bones that transfer sound from the eardrum to the inner ear.

mutation: a permanent change in a gene that occurs by chance.

myringotomy: a minor surgical procedure in which a small slit is made in the eardrum to allow fluid to drain from the middle ear.

-N-

nasal septum: the structure that divides the nose into the left and right sides.

nasality: abnormal flow of air through the nose during speech.

nasoalveolar molding (NAM): a nonsurgical method of reshaping the mouth, lip, and nostrils to lessen the severity of a cleft lip and palate surgery and enhance its results.

naso-endoscopy: a procedure in which a narrow flexible camera is inserted down through the nose to enable one to view the velopharyngeal (soft palate and back of the throat) closure.

nasogastric tube (NG): feeding tube that is inserted through the nose, down the esophagus, and into the stomach.

nasopharynx: part of the pharynx (throat) above the soft palate.

-O-

obstructive apnea: cessation of air flow for ten or more seconds because of an obstruction in the upper airway. Also known as obstructive sleep apnea (OSA).

obturator: a device worn in the mouth to decrease nasal air flow during speech.

occlusion: the relationship between upper and lower teeth when they are in contact. Refers to the alignment of teeth as well as the relationship of the dental arches.

occupational therapist: a professional who helps work on small muscle strength and coordination to improve self-care skills (activities of daily living).

open bite: the inability of the teeth of the upper and lower jaws to make complete contact when clenched.

orbits: the bony housing of the eyes.

otitis media: inflammation of the middle ear with accumulation of thick mucous-like fluid. Also known as a middle ear infection.

-P-

palate: the roof of the mouth including the front portion, known as the hard palate, and the back portion, known as the soft palate.

pharyngeal flap: surgical procedure designed to minimize hypernasality. A flap of mucosa (tissue lining the back of the throat) creates a “bridge” between the soft palate and the back of the throat.

Passey-Muir valve: a valve used to plug a tracheostomy so that air passes around the tube and into the mouth and nose.

pharynx: throat.

physical therapist: a professional who uses activities and exercises to help to reduce problems with movement and posture usually involving large muscles of the body.

plagiocephaly: refers to an asymmetric or lopsided head shape typically with flattening in one area caused by an external force or pressure.

post-operative (post-op): after an operation.

pre-existing condition: term used by insurance companies to indicate that a medical condition existed before the policy became effective.

pre-operative (pre-op): before a surgical procedure.

prosthesis: an artificial substitute for a missing body part.

ptosis: drooping; commonly used to refer to drooping eyelids and eyebrows.

-R-

radiography: photographic film showing images of the internal body parts and bones. Also known as an X-ray.

receptive language: the ability to understand language.

rhinoplasty: surgery to improve the appearance and/or function of the nose.

-S-

secondary surgery: surgery done after primary surgery to improve appearance or to correct additional problems.

sensorineural hearing loss: hearing impairment that originates in the inner ear or brain. May involve the cochlea and/or auditory (8th cranial) nerve.

sequence: a group of abnormalities caused by one development defect.

sleep apnea: at least thirty episodes during a seven-hour period of sleep during which the air flow stops for longer than ten seconds before an individual starts breathing again.

soft palate: fleshy area at the back of the roof of the mouth; contains the muscles that elevate the palate

during eating and speaking.

stridor: high pitched noise when breathing in.

submucous cleft: cleft in the palate that is not visible; there is a separation of the muscles of the soft palate, but not in the tissue covering the muscles (mucosa).

sutures: the type of binding or stitch that surgeons use to hold tissues together after an area of the body has been separated by injury or surgery; may also refer to the connection between parts of the skull.

syndrome: a disease or disorder that has more than one identifying feature or symptom.

synostosis: abnormal and premature joining of the skull bones.

-T-

temporomandibular joint (TMJ): joint between the side of the skull and the lower jaw.

torticollis: a limited range of motion in an infant's neck due to muscle tightness. The head often leans to one side because the neck muscles on that side are shortened. Usually corrected with physical therapy.

tracheotomy: the operation in which an opening is made into the windpipe.

trismus: limited opening of the mouth or prolonged spasms of the jaw muscles; lockjaw.

-U-

underbite: a dental condition in which the upper teeth are behind the lower teeth rather than in front of them.

unilateral: on one side (vs. bilateral or on both sides).

uvula: soft tissue hanging at the back of the soft palate.

-V-

velopharyngeal closure: the closing of abnormal connections between the nasal cavity and the oral cavity in order to direct the air used in speech through the nose instead of the mouth.

velopharyngeal incompetence: inability to achieve adequate velopharyngeal closure despite structures that may appear normal.

velopharyngeal insufficiency: a structural or functional disorder resulting in inadequate separation of the nasal and oral cavities during speech. Velopharyngeal insufficiency often results in a nasal sounding voice.

videofluoroscopy: a tape-recorded X-ray examination of the speech mechanism, focusing on the soft palate and walls of the throat. Used to evaluate velopharyngeal function.

-Z-

zygoma: cheek bone forming part of the orbit of the eye.

SECTION 2 TERMS RELATED TO INSURANCE

-A-

ambulatory care: medical care, rehabilitation therapies, and orthodontic and oral surgical care performed on an outpatient basis (non-overnight care) in hospital clinics, physician offices, day surgery centers, and emergency departments.

ancillary services: professional services such as laboratory tests, radiological exams, and rehabilitation therapies.

assignment of benefits: the procedure that physicians and medical providers follow to receive insurance payments directly.

-C-

capitation: a method of payment that represents a capped limit on benefits paid to a physician or health care facility by an insurance company for each patient.

case management: a method by which a health insurance plan manages how much they pay for the medical care of a patient by coordinating an individual's health care needs.

COBRA (Consolidated Omnibus Budget Reconciliation Act): guidelines in a federal law that give former employees, spouses, dependent children, and retirees the ability to continue their health coverage for a certain period of time at a group rate. There is a specific time limit to this type of coverage and you should check with your employer for details.

coinsurance: the amount you are required to pay above the covered portion of the health care cost, usually 20 or 30 percent. For example, if your insurance carrier pays 80 percent of the healthcare cost, the remaining 20 percent that becomes your responsibility is called coinsurance.

copayment: often called a “copay,” the set amount, determined by your health insurance policy, that you pay for health care services over and above the amount paid by your insurance.

CPT-Code (Current Procedural Terminology): the numerical code assigned to a medical procedure that is used by a health insurance company to determine how much to reimburse the provider of the procedure.

-D-

deductible: the amount you are required to pay annually for your health care expenses before your health insurance company will pay for services.

-E-

exclusions: health care services that are not covered under your health insurance plan.

Exclusive Provider Organization (EPO): a network of medical care providers which individuals are required to use in order to receive reimbursement. Unlike a Preferred Provider Organization or PPO (see below for definition), an EPO will not reimburse individuals for health care services performed outside of the designated network of providers.

external appeal/external review: an independent review that takes place when health care services have been denied based on the insurance carrier's determination that treatment is not medically necessary or is experimental. To ensure an unbiased review, an external review is performed by an organization not affiliated with your physician, insurance carrier, or family.

-F-

fee schedule: a list of numerical CPT codes that corresponds to specific dollar amounts that a health insurance company will pay for a particular service. This fee schedule is often not disclosed until after the health care services have been performed.

formulary: a list of medications covered by your insurance policy.

-H-

Health Maintenance Organization (HMO): a system of health care delivery offered by a prescribed list of providers. Often patients must remain within this list of providers to receive the full benefit of their coverage. The HMO often requires preapproval for doctor or specialist visits, surgical procedures, certain medications, and follow up care. Emergency care is usually exempt from this requirement.

-I-

International Classification of Diseases (ICD) codes: the standard way of identifying an illness or disease. Also known as a diagnosis code.

indemnity plans: a private health insurance policy that allows subscribers to choose any health care provider or facility. These plans often have a deductible that must be satisfied before costs are fully covered.

-M-

managed care: a health insurance plan that limits reimbursements, promotes less expensive forms of care, and limits access to services that they do not deem medically necessary.

medical necessity: medical treatment identified by your insurance company for accidental injury or illness that is considered necessary and not experimental, investigational, or cosmetic.

-P-

Point of Service (POS): a health insurance plan in which you can choose an in-network physician as your primary care provider. If you choose to see an out-of-network provider you will pay more of the cost unless the primary care provider makes the referral to that particular out-of-network service provider.

Preferred Provider Organization (PPO): a network of health care providers offering services at a reduced rate in exchange for being included in the organization. Your primary care physician (PCP) manages all referrals within the PPO, although some PPOs do not require a referral for specialty care. Unlike in an HMO, you are usually allowed to see out-of-network health care providers. However, PPO insurance providers often reimburse at lower rates for health care performed outside of the network.

primary care provider (PCP): the first provider, such as a pediatrician, internist, or family practitioner, that a patient sees for new health concerns and for the management of existing health problems. Some health insurance plans require you to obtain a referral from your PCP before seeing a specialist.

-U-

usual and customary reimbursement (UCR): the maximum amount a health insurance provider will pay for a medical procedure or service.

Utilization Review (UR) Appeal: your ability to appeal a decision made by a health insurance company if it has refused to cover health care services that it considers investigational, experimental, or not medically necessary.

SECTION 3 TERMS RELATED TO ENTITLEMENTS

-A-

Americans with Disabilities Act (ADA): a federal law that prohibits discrimination against people with physical or mental disabilities in employment, public places, hotels, theaters, and schools.

-C-

COBRA (Consolidated Omnibus Budget Reconciliation Act): a federal law that contains provisions giving former employees, retirees, spouses, and dependent children the right to continue their health coverage at group rates for a limited time period. It is advisable to check with the employer regarding the details of the coverage.

-D-

Department of Health and Human Services (HHS): the United States federal department that administers all federal programs dealing with health and welfare. HHS also has community-based offices that can provide resources regarding health-related issues and access to local services.

-E-

early childhood intervention: a system of coordinated services that promotes the child's growth and development and supports families during critical early years. The goals of early intervention are to provide appropriate therapies for children who may be at risk of having or have a disability to minimize developmental delays and maximize their chances of reaching normal developmental milestones. Early intervention begins at birth or first diagnosis and continues until age 3. Services are mandated through the Individuals with Disabilities Education Act (IDEA).

-F-

Family and Medical Leave Act (FMLA) of 1993: a federal labor law allowing an employee to take an unpaid leave of absence to care for a sick family member or a newborn. Under this law, an employee is entitled to 12 workweeks of leave per 12 months. Generally, FMLA ensures that all workers are able to take extended leaves of absence from work to handle family issues or illness without fear of being terminated from their jobs by their employers or being forced into a lower job upon their return.

-H-

The Health Insurance Portability and Accountability Act (HIPAA): a federal law enacted to help protect an individual's privacy and to govern who can and who cannot have access to personal medical information. One of the most important aspects of HIPAA is its guarantee that employees who change jobs and who have had insurance coverage for at least 12 months will not face restrictions (called "preexisting condition limitations") in what is covered when they enroll for health insurance at a new employer.

-I-

Individuals with Disabilities Education Act (IDEA): the federal law that mandates standards for the provision of educational services by public schools for children from birth to 21 years of age with physical or mental disabilities. These standards include the development of individualized education plans that outline the special services a child may need, such as mental health services or speech, physical, or occupational therapy. Early intervention programs are also made available under this federal law.

-M-

Medicaid: a medical insurance program that provides coverage for medical services. Medicaid is jointly funded by the states and the federal government and reimburses hospitals and physicians for providing care to people who cannot pay for their own medical expenses. This program also provides payment assistance for home care services.

-O-

Office for Civil Rights (OCR): this government organization ensures that people have equal opportunity to participate in and receive services, including health care, without facing unlawful discrimination. It also helps to protect the privacy of personal health information.

-R-

rehabilitation: the process of restoring skills to a person who has had an illness or injury. The rehabilitation process uses physical, occupational, and speech therapies to maximize self-sufficiency, and restore function to normal or as close to normal as possible.

-S-

Social Security: the comprehensive federal program of benefits for workers and their dependents. Benefits provided by this program include retirement benefits, survivor benefits, and disability benefits for eligible adults and children.

State Children's Health Insurance Program (SCHIP): a federal government program that gives states funds for providing health insurance to low-income families with children. The program is designed to cover uninsured children of families with modest incomes that are too high to qualify for Medicaid.

Supplemental Security Income (SSI): a program administered by the Social Security Administration to provide financial assistance for people with low incomes who are blind, aged, or have a disabling condition. Eligibility is based on income and need, not on past earnings. Children with disabling conditions are also eligible for this entitlement.

Selected Reading List

This chapter provides the names of publications written for adults and children. These publications include accounts by parents of children with facial differences or chronic illnesses, autobiographical accounts by individuals with facial differences, and books and articles written by health care professionals. You can find these publications in public libraries, bookstores, or online.

SECTION 1 PUBLICATIONS FOR PARENTS AND ADULTS

Organizations that provide informational publications:

Ameriface (P.O. Box 458, Crystal Lake, IL 60014; (888) 486-1209; www.ameriface.org). Publications include: *Apert, Crouzon and Other Craniosynostosis Syndromes*; *Making the Difference: Caring for the Newborn and Family Affected by Facial Disfigurement - An Orientation Package for Health Care Providers*; *My Newborn Has a Facial Difference*; *You, Your Child and the Craniofacial Team*.

American Cleft Palate-Craniofacial Association (104 South Estes Drive, Suite 204, Chapel Hill, NC 27514; (919) 933-9044; www.cleftline.org). *Parameters for evaluation and treatment of patients with cleft lip/palate or other craniofacial anomalies*.

Cleft Palate Foundation (1504 East Franklin Street, Suite 102 Chapel Hill, NC 27514; (919) 933-9044; www.cleftline.org). Publications include: *For Parents of Newborn Babies with Cleft Lip/Palate (available in Spanish)*; *Cleft Lip and Cleft Palate: The First Four Years (available in Spanish)*; *Cleft Lip and Cleft Palate - The Child from Three to Twelve Years*; *Information for the Teenager Born with a Cleft Lip and/or Palate*; *Feeding an Infant with a Cleft (available in Spanish)*; *The Genetics of Cleft Lip and Palate*.

Fact Sheets: *Information about Choosing a Cleft Palate or Craniofacial Team*; *Information about Crouzon's Disease*; *Information about Dental Care*; *Information about Financial Assistance*; *Information about Pierre Robin Malformation Sequence*; *Information about Submucous Cleft*; *Information about Treacher Collins Syndrome*; *Information about Treatment for Adults with Cleft Lip and Palate*.

Informational Books:

Brooks, R. and Goldstein, S. *Raising Resilient Children: Fostering Strength, Hope, and Optimism in Your Child*. New York, NY: Contemporary Books, 2001.

Des Jardins, C. *How to Get Services by Being Assertive: For Parents of Children with Disabilities and their Helpers*. Chicago, IL: Family Resource Center on Disabilities, 1993. This book is only available from the Family Resource Center on Disabilities: 20 East Jackson Boulevard, Room 900, 60604; (312) 939-3513.

Foxman, P. *The Worried Child: Recognizing Anxiety in Children and Helping Them Heal*. Alameda, CA: Hunter House Publishers, 2004.

Garber, S., Garbar, M., Spizman, R. and Spizman, R.E. *Good Behavior Made Easy Handbook*. New York, NY: Villard Books, 1992.

Goldman, L. *Raising Our Children to be Resilient: A Guide to Helping Children Cope with Trauma in Today's World*. New York, NY: Brunner-Routledge, 2005.

Haber, J. *Bully Proof Your Child for Life: Protect Your Child from Teasing, Taunting, and Bullying for Good*. New York, NY: Penguin Group (USA) Inc., 2007.

Lavin, J. *Special Kids Need Special Parents: A Resource for Parents of Children with Special Needs*. New York, NY: Berkley Books, 2001.

Marshak, L.E. and Preznant, F.P. *Married with Special Needs Children: A Couples' Guide to Keeping Connected*. Bethesda, MD: Woodbine House, 2007.

Miller, N. *Nobody's Perfect: Living and Growing with Children Who Have Special Needs*. Baltimore, MD: Brookes Publishing Co., 1994.

Moffitt, K., Reiss, J. and Nackashi, J. *Special Children, Special Care*. Tampa, FL: Florida Diagnostic and Learning Resources System of the University of South Florida. For a copy of this workbook, contact the University of South Florida Bookstore: General Books Department, 4204 East Fowler Avenue, Tampa, FL 33620-6550; (813) 974-2631.

myFace. *Genetics: A Guide for Parents of Children with Facial Differences*. New York, NY: 2008. For a copy of this publication, please contact myFace: 333 East 30th Street, Lobby Unit, New York, NY 10016; (212) 263-6656; www.myFace.org.

myFace. *Parenting: A Guide for Parents of Children with Facial Differences*. New York, NY: 2008. For a copy of this publication, please contact myFace: 333 East 30th Street, Lobby Unit, New York, NY 10016; (212) 263-6656; www.myFace.org.

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Paige-Carlsson, N. and Levin, D. *Before Push Comes to Shove: Building Conflict Resolution Skills with Children*. St. Paul, MN: Red Leaf Press, 1998.

Parr, T. *It's Okay to Be Different*. Boston, MA: Little Brown Publishing, 2001.

Powell, T. and Gallagher, P.A. *Brothers & Sisters: A Special Part of Exceptional Families*. Baltimore, MD: Brookes Publishing Company, 2006.

Project School Care. *Working Towards a Balance in Our Lives: A Booklet for Families of Children with Disabilities and Special Health Care Needs*. Boston, MA: Children's Hospital Boston, 1992.

Reich, E. *Treacher Collins Syndrome: An Overview*. Norwich, VT: Treacher Collins Foundation, 1992.

Personal Stories:

Abbott, M. *My Face*. New York, NY: Forward Face, 1998.

Baskin, A. and Fawcett, H. *More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs*. Bethesda, MD: Woodbine House, 2006.

Berkowitz, S. *Uncommon Fathers: Reflections on Raising a Child with a Disability*. Bethesda MD: Woodbine House, 1994.

Berkowitz, S. *The Cleft Palate Story*. Carol Stream, IL: Quintessence Publishing Co., 1994. This book is available in the "online library" at www.smiletrain.org.

Breslow, J. with a narration by K. Breslow. *Funny Face*. New York, NY: myFace, 2001. For a copy of this publication, contact myFace: 333 East 30th Street, Lobby Unit, New York, NY 10016; (212) 263-6656; www.myFace.org.

Charkins, H. *Children with Facial Difference: A Parent's Guide*. Bethesda, MD: Woodbine House, 1996.

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Hallman, T. Sam: *The Boy Behind the Mask*. New York: Putnam Adult, 2002.

Klein, S.D. and Schleifer, M.J., eds. *It Isn't Fair! Siblings of Children with Disabilities*. Westport, CT: Greenwood Publishing Group, 1993.

Krementz, J. *How It Feels to Live with a Physical Disability*. New York, NY: Simon & Schuster. 1992.

Lipman, K. *Don't Despair Cleft Repair*. Naples, FL: Lipman Productions, 1999.

Marsh, J. and Boggis, C., eds. *From the Heart: On Being the Mother of a Child with a Disability*. Bethesda, MD: Woodbine House, 1995.

McDermot, J. *Babyface: A Story of Heart and Bones*. Bethesda, MD: Woodbine House, 2001.

McHugh, M. *Special Siblings: Growing Up with Someone with a Disability*. Baltimore, MD: Paul H. Brookes Publishing Co., 2003.

Pinkava, M.J. *A Handful of Hope: Helpful Suggestions for Grandparents of Children with Disabilities*. Phoenix, AZ: Pilot Parent Partnerships, 1991.

Roche, D. *The Church of 80% Sincerity*. New York, NY: Penguin Group (USA) Inc., 2008.

Schafritz, L. *Face Value: Coping with Facial Disfigurement*. Los Angeles, CA: Face Value, 1994.

Simons, R. *After the Tears: Parents Talk about Raising a Child with a Disability*. San Diego, CA: Harcourt Brace Jovanovich, 1987.

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Civardi, A. *Curious George Goes to the Hospital*. Tulsa, OK: EDC Publishing, 1998.

DePino, C. *Blue Cheese Breath and Stinky Feet: How to Deal with Bullies*. Washington, DC: Magination Press, 2004.

Dooley, V. *Tubes in My Ears: My Trip to the Hospital*. New York, NY: Mondo Publishing, 1996.

Duncan, D. *When Molly was in the Hospital: A Book for Brothers and Sisters of Hospitalized Children*. Windsor, CA: Rayve Productions Inc., 1994.

Emberley, E. *Bye-Bye, Big Bad Bullybug*. New York, NY: Little Brown Books, 2007.

Fisbaough, M. *Someone Like Me - A Booklet for Children Born with Cleft Lip and Palate*. Brownsburgh, IN: Riley Hospital, 1992.

Gainer, C. *I'm Like You, You're Like Me - A Child's Book About Understanding and Celebrating Each Other*. Minneapolis, MN: Free Spirit Publishing, 1998.

Goldblatt, R. *The Boy Who Didn't Want to Be Sad*. Washington, DC: Magination Press, 2004.

Hale, N. *Oh Brother! Growing Up with a Special Needs Sibling*. Washington, DC: Magination Press, 2004.

Hautzig, D. *A Visit to the Sesame Street Hospital*. New York, NY: Random House, 1985.

Johnson, M. *Let's Talk About Going to the Hospital*. New York, NY: Powerkids Press, 1998.

Kaufman, M. *Q & A's for Teens Living with Chronic Illness and Disabilities*. Ontario, Canada: Firefly Press, 2005.

Lanczak, H. *Mookey the Monkey Gets Over Being Teased*. Washington, DC: Magination Press, 2006.

Hallman, T. *Sam, the Boy Behind the Mask*. New York: G.P. Putman & Sons, 2002.

Maier, I. *When Lizzy was Afraid of Trying New Things*. Washington, DC: Magination Press. 2005.

Meyer, D. and Vadasy, P. *Living with a Brother or Sister with Special Needs: A Book for Sibs*. Seattle, WA: University of Washington Press, 2000.

Meyer, D., ed. *Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs*. Bethesda, MD: Woodbine House, 1997.

Mills, J.C. *Little Tree: A Story for Children with Serious Medical Problems*. Washington, DC: Magination Press. 2003.

Moses, A. *At the Hospital*. Mankato, MN: Child's World. 1997.

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