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Parameters

For Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Differences

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American Cleft Palate–Craniofacial Association

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IMPORTANT NOTICE:
Individual variations in the condition of the patient, status of patient and family, and the response to treatment, as well as other circumstances, mean that the optimal treatment outcome for some patients may be obtained from practices other than those recommended in this document.

Revised Edition, January 2018
Revisions were made to all sections in the document and were approved by ACPA members by ballot, fall 2016.

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A revision to the dental care section and the genetics/dysmorphology services section of the document was approved by ACPA members by ballot, fall 2009.

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A revision to the speech-language pathology services section of the document was approved by ACPA members by ballot, fall 2007.

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Revisions were made to audiologic care, cleft lip/palate surgery, craniofacial surgery and maxillofacial surgery, dental care, nursing care, otolaryngologic care, psychological and social services, and speech-language services and were approved by ACPA members present and voting at the April 2000 Annual Business Meeting.

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PREFACE

In June of 1987, the Surgeon General of the United States issued a report on children with special health care needs (Koop, 1987). The central theme of the report was that these children require comprehensive, coordinated care provided by health care systems that are readily accessible and responsive to the individual needs of the patients and their families. Among other points, the Surgeon General called for 1) facilitation of parent/professional collaboration in the health care of children, 2) sharing of unbiased and complete information about children with their parents, 3) provision of emotional and financial support for families, 4) sensitivity to cultural differences, 5) encouragement of parent-to-parent support, 6) incorporation of the developmental needs of infants, children, and adolescents into health care plans, 7) assurance of the availability of comprehensive services including social, emotional, and cognitive aspects of health care, and 8) an interdisciplinary approach to care. The following actions were recommended: Commitment to children with special needs; encouragement of community-based services; adequate preparation of providers of services; formation of coalitions to improve delivery of services; development of guidelines to control costs of services; establishment of protocols to assess quality of care; encouragement of adequate health care financing; and conduct of research and dissemination of information about aspects of health care.

Recognizing that children with craniofacial birth differences, including cleft lip and cleft palate, are among those children with special health care needs, the Maternal and Child Health Bureau provided funding (MCJ-425074 - "Development of Standards for Health Care of Infants, Children, and Adolescents with Craniofacial Anomalies") to the American Cleft Palate-Craniofacial Association for the purpose of identifying recommended practices in the care of patients with craniofacial differences. This work began in May 1991 with a consensus conference in which 71 individuals participated. The majority of the participants were professionals experienced in the diagnosis and treatment of craniofacial differences and related disorders. They were selected from the fields of anatomy, audiology, craniofacial surgery, genetics, nursing, oral and maxillofacial surgery, orthodontics, otolaryngology, pediatric dentistry, pediatrics, plastic surgery, prosthodontics, psychology, social work, speech-language pathology, and speech science. The remainder of the participants were selected to represent patients and their families, multilingual-multicultural interests, and government agencies involved in the funding of care for such patients. Following four days of presentations by experts and discussion by participants, the attendees voted by ballot on each of 386 resolutions that the grant project committee had distilled from the written records of the proceedings. The recommendations on which at least 75% of the conference attendees concurred* were included in a draft of a parameters of practice document. Copies of the document were then distributed for both select and widespread peer reviews; subsequent revisions were made by the committee in response to reviewers' comments. The revised document was returned to the participants in the consensus conference for ratification and was subsequently approved as American Cleft Palate-Craniofacial Association policy by the Executive Council.

Reference

Surgeon General's Report: Children with special health care needs. Office of Maternal and Child Health, U.S. Department of Health and Human Services, Public Health Service, June 1987.

* In a few instances in which the recommendation(s) involved specialty-specific issues and individuals outside that specialty were neutral in their responses, the recommendation(s) were based on at least a 75% concurrence of individuals representing that specialty.

INTRODUCTION

There are numerous types of congenital craniofacial differences, the most common of which is cleft lip and/or palate. In the United States, this condition affects approximately 7,000 newborns each year (Parker et al., 2010). Roughly one-half of these infants have associated malformations, either minor or major, occurring in conjunction with the cleft (Jones, 1988; Rollnick and Pruzansky, 1981; Shprintzen et al., 1985). Although the incidence figures for more complex conditions or syndromes such as Apert syndrome, Crouzon syndrome, mandibulofacial dysostosis or craniofacial microsomia are much lower than that for cleft lip and/or palate, the impact of craniofacial birth differences must be viewed in terms of the aggregate effect rather than the impact of any single entity. This impact is twofold: the patient and family and on society as a whole. The health and well-being of all of these children is dependent upon the clinical expertise of those who serve them. Quality of care positively impacts society as a whole by allowing the affected individual, through ongoing and excellent medical intervention, to make a positive contribution within their community.

Although the treatment of children with cleft lip and/or palate and other types of craniofacial differences in the United States has improved dramatically, many children still receive care that is substantially inferior to what can or should be provided. Inadequate care results from diagnostic errors, failure to recognize and treat the full spectrum of health problems associated with these differences, unnecessary and poorly timed treatment, and inappropriate or poorly performed procedures. Each of these persistent problems was addressed in the course of the consensus conference.

Several fundamental principles underlie the recommendations of the conference attendees regarding the optimal care of patients with craniofacial differences, regardless of the specific type of disorder:

I. Management of patients with craniofacial differences is best provided by an interdisciplinary team of specialists.
II. Optimal care for patients with craniofacial differences is provided by teams that see sufficient numbers of patients each year to maintain clinical expertise in diagnosis and treatment.
III. The optimal time for the first evaluation is within the first few weeks of life and, whenever possible, within the first few days. However, referral for team evaluation and management is appropriate for patients at any age.
IV. From the time of the first contact with the child and family, every effort must be made to assist the family in adjusting to the birth of a child with a craniofacial difference and to the consequent demands and stress placed upon the family.
V. Parents/caregivers must be given information about recommended treatment procedures, options, risk factors, benefits, and costs to assist them in (a) making informed decisions on the child's behalf, and (b) preparing the child and themselves for all recommended procedures. The team should actively solicit family participation and collaboration in treatment planning. When the child is mature enough to do so, he or she should participate in treatment decisions.
VI. Treatment plans should be developed and implemented on the basis of team recommendations.
VII. Care should be coordinated by the team but should be provided at the local level whenever possible; however, complex diagnostic and surgical procedures should be restricted to centers with the appropriate facilities and experienced care providers.
VIII. It is the responsibility of each team to be sensitive to linguistic, cultural, ethnic, psychosocial, economic, and physical factors that affect the dynamic relationship between the team and the patient and family.
IX. It is the responsibility of each team to monitor both short-term and long-term outcomes. Thus, longitudinal follow-up of patients, including appropriate documentation and record-keeping, is essential.
X. Evaluation of treatment outcomes must take into account the satisfaction and psychosocial well-being of the patient as well as effects on growth, function, and appearance.

The remainder of this document is divided into the following sections:

(1) interdisciplinary teams: composition, qualifications of team members, and general responsibilities of teams; (2) contemporary practices of the team during the early months of life of the patient; and (3) longitudinal evaluation and treatment, listing general guidelines and contemporary practices as they pertain to professional specialty areas.

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INTERDISCIPLINARY TEAMS

Composition

The staff of the interdisciplinary team may include but not be limited to individuals from the following areas of professional practice: anesthesiology, audiology, diagnostic medical imaging/radiology, genetic counseling, genetics/dysmorphology, neurology, neurosurgery, nursing, ophthalmology, oral and maxillofacial surgery, orthodontics, otolaryngology, pediatrics, pediatric dentistry, physical anthropology, plastic surgery, prosthodontics, psychiatry, psychology, social work, and speech-language pathology. Consultation with other professionals may also be appropriate. The specific staff will be determined by the availability of qualified personnel and by the types of patients served by the team. When the team cannot provide all of the types of examinations or other services required by its patients, team members are responsible for making appropriate referrals and for communicating with those to whom patients are referred to facilitate the implementation of appropriate and coordinated treatment plans.

Qualifications of Team Members

The paramount interest of both the Bureau of Maternal and Child Health and the American Cleft Palate-Craniofacial Association is the quality of care for patients. It is thus essential that all team members be trained and experienced in the care of patients with craniofacial differences. However, this document does not address the scope of practice of individual professional specialties. The educational and experiential requirements for the specialties represented on teams are variously determined by their own specialty boards, professional associations, state licensing boards, etc. These requirements are continually subject to change. Each team must take responsibility for assuring that team members not only possess appropriate and current credentials but also have requisite experience in evaluation and treatment of patients with craniofacial differences. Teams should assist members in keeping current with their specialties by supporting and encouraging their participation in continuing education activities and attendance at professional meetings.

Team Responsibilities

The principal role of the interdisciplinary team is to provide integrated case management to assure quality and continuity of patient care and longitudinal follow-up. Each patient seen by the team requires comprehensive, interdisciplinary treatment planning to achieve maximum habilitation with efficient use of parent and patient time and resources. Each interdisciplinary team should do the following:

- Maintain an office with a secretary and/or coordinator and a listed telephone number.
- Maintain centralized and comprehensive records on each patient, including histories, diagnoses, reports of evaluations, treatment plans, reports of treatment, and supporting documentation, such as photographs, radiographs, dental models, and audiotaped speech recordings.
- Designate a coordinator who facilitates the function and efficiency of the team, ensures the provision of coordinated care for patients and families, and assists patients and families in understanding, coordinating, and implementing treatment plans.
- Designate a member(s) to make initial contact with the patient and/or family and also with direct care providers, as appropriate.
- Evaluate patients at regularly scheduled intervals, the frequency and specific content of those evaluations being determined by the condition and needs of the patient and family.
- Hold regularly scheduled face-to-face meetings for discussion of findings, treatment planning, and recommendations for each patient.
- Develop a longitudinal treatment plan for each patient that is modified as necessitated by craniofacial growth and development, treatment outcomes, and therapeutic advances.
- Weigh all treatment decisions against the expected outcomes and related factors, such as facial growth, hearing, speech, dentition, and psychosocial impact on patient and family.
- Be aware that conventional skull radiographs may be used for screening purposes. The total dose of radiation should be kept in mind when obtaining repeat studies. CT scanning and magnetic resonance imaging may be obtained as needed. Such imaging techniques are to be used in preoperative planning and postoperative evaluations.
- Understand that although some operative procedures (i.e., placement of myringotomies) may be classified as minor procedures, the potential psychological impact on the child and family attendant upon any surgical procedure must be taken into consideration, particularly when the child is subjected to repeated procedures. All procedures should be preceded by appropriate exchange of information with the patient and family and every attempt made to allay fears regarding effects of anesthesia, the immediate postoperative course, postoperative precautions, etc.
- Communicate the treatment recommendations to each patient and family in written form as well as in face-to-face discussion.

- Provide updated information to families as the treatment plan unfolds and repeat information frequently enough to assure its assimilation.
- Demonstrate sensitivity and flexibility in provision of care to accommodate linguistic, cultural, and ethnic diversity among patients and their families, ensuring that appropriate interpreters are available to assist in both verbal and written communication.
- Assist families in locating resources for financial assistance necessary to meet the needs of each patient.
- Communicate on a routine and ongoing basis with direct care providers in the home community, and invite these care providers to participate in team meetings involving their patients.
- Perform regular, formal assessments of the quality of patient care with participation by each member of the team and, when appropriate, utilize external peer review. Teams should also conduct periodic surveys of patient satisfaction.
- Maintain a reliable list of resources for any services that are either not provided by the team itself or are better provided at the community level.
- Assist families in planning for treatment in a new geographic location by referring them to an interdisciplinary team in that area and facilitating contact with the new team.
- Provide assistance to adolescents and their families in planning for the transition of their care as they enter adulthood.
- Provide adult patients with continued opportunities for team care.
- Promote early identification of children with craniofacial differences through programs designed to inform delivery room personnel, neonatal care personnel, and primary care providers in the community about these birth differences.
- Provide educational programs for hospital personnel and primary care providers by addressing feeding and other critical aspects of early health care for children with craniofacial differences.
- Promote understanding of, and sensitivity to, the needs of patients by providing educational information about craniofacial differences and related disorders to parents and patients, to other professional people, and to the general public.
- Promote understanding of, and sensitivity to, the concerns of both parents, recognizing that each parent may have separate concerns.
- Promote understanding among care team members of diverse family units.
- Aid in the formation and encouragement of parent-run support groups, and encourage cooperation with hospital visitation programs by trained volunteers.

NEONATAL PERIOD AND INFANCY

As stated in principle III, the optimal time for the first evaluation of a child with congenital differences is within the first few days of life. Subsequent evaluations should be scheduled at regular intervals, the frequency and specific content of each of those evaluations being determined by the condition and needs of the individual infant and family.

Team Practices

One or more members of the interdisciplinary team - typically the team nurse or other identified feeding specialist(s) - should assume responsibility for providing the following services based on the needs of the infant:

- Contacting the family immediately after referral to provide assistance with feeding as well as offering other basic information in conjunction with the primary care provider, i.e., the pediatrician or family physician.
- Ensuring weekly assessment of nutritional intake and weight gain during the first month of life.
- Maintaining support for the family through telephone calls, office visits, and, when appropriate, referral for home health services.
- Reinforcing information provided by the hospital at the time of discharge regarding techniques of airway maintenance, including, but not limited to, positioning of the infant, nasogastric tube insertion, care of a tracheostomy, cardiac and/or apnea monitoring.
- Assisting the family with follow-up otolaryngological and/or audiological care. Assisting in arranging newborn hearing screen if not performed at the time of birth.

At the time of the infant's first visits and based on the individual needs of each infant and family, the team should:

- Obtain a history of prenatal and postnatal development.
- Provide a full pediatric evaluation including nutritional and feeding assessments, and growth and development.
- Provide instruction and educational materials on feeding, and offer other information, such as the availability of special feeding devices. (Note: The mother's choice of feeding method should be supported as long as oral feeding has been evaluated for safety and the infant is able to meet all of his/her nutritional needs.)
- Perform a genetic/dysmorphology screening with subsequent provision of, or referral for, a complete genetic evaluation as necessary. If a recommendation is to be made for a full genetic evaluation and counseling, consideration should be given to the family's emotional status. If the family declines the recommendation of the team for genetic evaluation and/or counseling, this information should be documented in the patient's record.
- Arrange for any evaluations pertinent to the genetic/dysmorphologic diagnosis, including, but not limited to, specific gene study, genetic panels, imaging studies, chromosome-based molecular analysis, ophthalmological evaluation, etc.
- Perform or arrange for an otolaryngologic evaluation.
- Perform or arrange for an audiologic evaluation.
- Instruct the caretakers regarding symptoms of otologic disease, hearing loss, and sleep apnea.
- Arrange for otolaryngological, surgical, and/or cardiopulmonary assessments if the infant is at risk for respiratory obstruction or sleep apnea.
- Be aware that mandibular distraction may be indicated in infants with upper airway obstruction secondary to obstructive mandibular micrognathia.
- Offer information to parents, as appropriate, about normal speech and language development, speech and language impairments for which the child may be at risk, and ways in which they may facilitate speech and language development.
- Conduct an assessment of prelinguistic speech-language development.
- Conduct or arrange for a psychosocial interview of the family to obtain information regarding the family history and adjustment of the family to the child. This information needs to be culturally and linguistically sensitive to the family. Assist the family in the identification of resources available for emotional and financial needs.
- Provide examination by a dental specialist to evaluate factors that may influence surgical management, to assist in treatment planning, and to obtain baseline diagnostic records.
- Provide counseling on care of the oral cavity and prevention of dental caries, especially nursing bottle caries.
- Provide examination by a surgeon and consultation among team members and family members regarding management procedures.
- Consult with an appropriate dental specialist for cleft lip taping and/or presurgical orthopedics, including, but not limited to, nasal alveolar molding (NAM).
- Provide families with contacts to appropriate parent-run support groups.

The team should monitor the child's development throughout the first year of life, and provide or refer for any required interventions. Areas of specific concern include (a) height, weight gain, nutrition, feeding disorders and growth; (b) continuity

of routine pediatric care, including immunizations; (c) motor, cognitive, and social development; (d) speech and language development; (e) otologic health; (f) hearing status; (g) parent-child adaptation, parental skills, behavior management, and nurturance; (h) the condition of the developing dentition and supporting tissues, with counseling regarding early oral hygiene and prevention of nursing caries; (i) the physical status of the child as it pertains to readiness for surgical management; and (j) modifications of the treatment plan as necessitated by any additional information (such as more complete genetic/dysmorphologic diagnoses or new developments in family status).

LONGITUDINAL EVALUATION AND TREATMENT

An ongoing relationship between the team, patient, and family allows for longitudinal monitoring of progress and permits the identification of new concerns on a timely basis. Even when the first team visit takes place later in childhood or adulthood, optimization of care requires regular team evaluations for assessment of treatment outcomes and updating treatment plans. Continuity of care enhances the evaluation and treatment process for patients of any age.

Audiologic Care

Individuals with craniofacial differences may have congenital conditions of the outer, middle, and/or inner ear structures. Those patients with a cleft palate are at an increased risk for middle ear disease. Hearing loss is a possible consequence of these ontological pathologies. The hearing loss may be permanent or intermittent, and it may range in degree from mild to severe. Hearing loss can have a detrimental effect on speech and language development, academic and vocational performance, and psychological and social well-being. For these reasons, individuals with a craniofacial difference require routine audiology surveillance.

- A record of the newborn's hearing screen should be obtained after discharge from the birth facility. If the newborn did not pass the screen, a complete audiological diagnostic evaluation should be performed by three months of age.
- The timing of audiological follow-up examinations should be determined on the basis of the child's history of ear disease and/or hearing loss. Audiological follow-up examinations should continue through adulthood as necessary.
- Audiological evaluations should begin at approximately nine months of age, and include a behavioral audiologic evaluation. Behavioral tests should be repeated at least every six to twelve months until the child is five years of age. After age five, if the hearing test is consistently within normal limit, then audiologic evaluations should be conducted annually until adolescence.
- If an individual with a craniofacial difference presents with a hearing loss of any type or degree (conductive, sensorineural, mixed, mild, moderate or severe) the schedule of audiological testing will change based on the audiologist's discretion.
- At each audiological visit, behavioral and physiologic audiological testing should be conducted. Behavioral evaluations include pure tone and, when possible, speech audiometry. Physiologic tests should include acoustic emittance testing (tympanometry and middle ear reflexes) and otoacoustic emissions (OAEs).
- All children undergoing myringotomies and placement of ventilation (pressure equalizing) tubes should be seen for audiologic assessment regularly.
- When a persistent hearing loss is identified, amplification (hearing aid, bone anchored hearing aids (BAHA), cochlear implants, and auditory training or FM systems) should be considered.
- When a hearing loss occurs in the presence of microtia or atresia of the outer or middle ear, either unilaterally or bilaterally, conventional bone conduction amplification should be considered. Depending upon the degree of loss, candidacy, and patient preference, a bone anchored hearing system (auditory osseointegrated implant) may be considered as a treatment option.
- Once amplification has been provided, routine audiologic follow-up is necessary to monitor hearing status and the function of the amplification system.
- For any child with a documented hearing loss, an immediate referral should be made to the child's school district for appropriate educational services.

Cleft Lip/Palate Surgery

In addition to primary surgical closure of the cleft lip and cleft palate, many patients will require secondary surgical procedures involving the lip, nose, palate, and jaws. These procedures usually are staged from infancy through adulthood. In all cases, surgical techniques should be individualized according to the needs and condition of the patient. Surgical procedures should be coordinated to minimize the number of anesthetic exposures and hospitalizations. Evaluation of complications (morbidity and mortality) of cleft lip and cleft palate repairs should be completed on an annual basis and subjected to peer review. The quality of surgical outcome depends upon the knowledge and skills of the cleft care team.

Primary Cleft Lip/Palate Surgery:

- It is highly recommended that an experienced pediatric anesthesiologist must be present for all surgical procedures involving children.
- Surgical repair of the cleft lip is usually initiated within the first 12 months of life and may be performed as early as is considered safe for the infant.
- Presurgical maxillary orthopedics to improve the position of the maxillary alveolar segments and/or enhance the nasolabial aesthetic outcomes prior to surgical closure of the cleft lip may be indicated for some infants.
- The nasal difference is an integral part of the cleft lip. Depending on the severity, primary rhinoplasty may be done at the time of the primary cleft lip repair.

- A preliminary cleft lip adhesion is a procedure that may be used in selected patients preceding definitive cleft lip repair.
- The goal of cleft lip repair is to restore the normal function and anatomical features.
- In the typically-developing child, the cleft palate should be closed by the age of 18 months and preferably earlier when possible.
- The goal of cleft palate surgery is to achieve normal function for speech and swallow. Repair of the cleft of the soft palate must include muscle reconstruction.
- Patients with submucous cleft palate should be monitored closely, and their submucous cleft palate should be repaired only if there is evidence of feeding, otologic, or speech problems.

Secondary Cleft Lip/Palate Surgery:

- Secondary cleft lip/palate surgery and/or surgery for velopharyngeal dysfunction should be performed only after evaluation (imaging) of the velopharyngeal mechanism during speech. Input from speech-language pathology and other team members should be obtained prior to this surgery.
- Tonsillectomy and/or adenoidectomy may also be indicated to permit safe performance of a pharyngeal flap or other type of pharyngoplasty.
- The patency of the nasal airway should be considered when planning either nasal reconstructive procedures or secondary velopharyngeal operations.
- Surgical or prosthetic closure of palatal fistulae may be needed if the fistulae are symptomatic.
- The timing of bone grafting of the alveolar cleft should be determined by the stage of dental development. The graft should be placed before the eruption of the permanent maxillary teeth in the region of the cleft. However, in patients who have been lost to follow up or are late in presenting to the team for alveolar bone grafting, this surgery may need to take place after full eruption of the permanent teeth. The timing of the operative procedure should be determined in collaboration with the team orthodontist. Autogenous bone should be used when tooth movement through the graft is anticipated.
- Although rhinoplasty and nasal septal surgery are usually advocated only after completion of nasal growth, earlier intervention for reasons of airway problem or nasal tip difference may be indicated. Repair of the cleft lip nasal difference can be accomplished with limited external incisions on the nose.
- The timing of nasal surgery should be discussed with the patient and parents so that the goals are understood and expectations are realistic.

Craniofacial Surgery and Maxillofacial Surgery

The complex nature of many types of craniofacial differences often necessitates multiple operative procedures at different stages of development. Reduction of morbidity and mortality from craniofacial operations requires establishment of a dedicated surgical team, frequent performance of operative procedures by that team, and adequate hospital facilities. Longitudinal follow-up is necessary for these patients even when the intervention has been successful with respect to the anatomical difference.

- Initial evaluation of cranial vault conditions should include a pertinent history and physical examination by team members who are specialists, including, but not limited to, genetics/dysmorphology, neurosurgery, ophthalmology, and craniofacial surgery.
- The specific components of the pre-, peri-, and postoperative evaluations of craniofacial surgery should be based upon the type of difference and the craniofacial zone(s) affected.
- For patients with isolated orbitocranial differences, including differences of shape and orbital position, the initial evaluation should include: pertinent history and physical examination by team members who are specialists, including, but not limited to, genetics/dysmorphology, neurosurgery, ophthalmology, and craniofacial surgery
- Timing of surgery, including distraction osteogenesis, for orbital craniofacial differences depends on associated soft tissue differences, functional impairments, and psychosocial concerns.
- An experienced pediatric anesthesiologist must be present for all surgical procedures involving children.
- Appropriate intensive care facilities must be available for all patients undergoing craniotomy or any procedure that might compromise the airway.
- Patients should be followed at regular intervals at least into adolescence to monitor cranial and facial growth, overall development, neurological status, ocular function, speech and hearing, and psychosocial adjustment.
- For patients with microtia, surgical reconstruction of the external ear, auditory canal, and middle ear are treatment options. Microtia reconstruction requires a staged surgical approach. Infrequently, the use of ear prostheses, which may be attached with adhesive or osseointegrated implants, is an alternative. The choice depends upon the medical condition and patient preference. Use of the osseointegrated implants, however, may compromise future surgical external ear reconstruction.
- In the case of surgical procedures that may alter dental occlusion, model surgery and prediction tracings should be completed in the treatment planning process.
- Orthognathic surgery (and/or distraction osteogenesis) is indicated when orthodontic treatment cannot achieve functional and/or acceptable esthetic occlusion and facial harmony. Such surgery should be timed to minimize any adverse effect on possible subsequent growth, and the timing should be determined in consultation with the team. Whenever possible, orthognathic surgery

should be delayed until physical maturation is essentially completed.
- Earlier surgery may be indicated when there are serious concerns regarding a compromised airway, jaw function, speech, or psychosocial adjustment. However, the patient and family must understand that additional procedures may be required to optimize the outcome. Secondary procedures including distraction osteogenesis may be necessary to correct residual differences of the mandible, maxilla, orbits, zygoma, forehead, and nose.
- If mandibular ankylosis is present, surgical release should be carefully considered and integrated with a comprehensive plan including postoperative physical therapy. The child's ability to participate in postoperative therapy should be considered during this treatment planning. Both surgical intervention and subsequent physical therapy may be necessary to facilitate mandibular development, improve the airway, or ameliorate feeding difficulties.

Dental Care

Patients with craniofacial differences require multi and interdisciplinary dental services as a direct result of the medical condition and as an integral part of the habilitative and rehabilitative process.

- Infant impressions, photographs, and imaging (3D soft tissue) in cases where infant orthopedics are under consideration.
- For parents expecting a child with cleft lip and/or palate, prenatal counseling should involve a craniofacial orthodontist (or appropriately trained clinician) who can discuss with the parents the types of infant orthopedic services available and the rationale for using infant orthopedics prior to initial cleft lip repair.
- For any individual with a craniofacial difference, an early consultation with a pediatric dentist is recommended.
- During the rehabilitative process from infancy to adulthood, the patient and family may encounter different dental services. These services may include but not be limited to: a craniofacial orthodontist, pediatric dentist, oral and maxillofacial surgeon, and a maxillofacial prosthodontist.
- Provision of dental services for these patients includes primary care and routine dental care. Early in life, these services are best provided by a pediatric dentist familiar with the needs of this population.
- Dental care should occur within six months of the eruption of the first tooth (and no later than twelve months of age) and continue regularly throughout life.
- As the child ages, the routine dental needs may be switched over to a general dentist based on the recommendations of the pediatric dentist and team in general.
- Dental services include but are not limited to: dental examinations, caries control, preventive and restorative dentistry, and prosthetic dental treatment as needed.
- Regular, ongoing dental evaluations should also include close monitoring for periodontal disease, differences of the dentition, and eruption disturbances.
- Prosthetic appliances may be required in some cases. These may include but not be limited to: obturator to close fistulae, speech appliance for nonsurgical treatment of velopharyngeal dysfunction, and teeth bearing prosthesis.

Orthodontic Services

Patients with craniofacial differences require orthodontic services as a direct result of the congenital medical condition and as an integral part of the habilitation and rehabilitation process. Contact with a craniofacial orthodontist may begin prenatally if the family has received a diagnosis of having a cleft lip, cleft lip and alveolus, or cleft lip and cleft palate. Prenatal counseling should review the rationale for the use of infant orthopedics. Regular, ongoing contact should be continued with the craniofacial orthodontist to monitor growth, position, and size of the skeletal and dental components, and dental hygiene, allowing for the determination of the optimal time for intervention. Active treatment is typically accomplished in a series of phases with each phase having specific objectives. These phases are typically in infancy, primary dentition, transitional dentition, and permanent dentition. Diagnoses and treatment planning requires a variety of diagnostic records as well as a thorough clinical examination. Ongoing records are obtained in a serial fashion to monitor craniodentofacial growth and development, as well as the results of ongoing treatment. When indicated, orthodontic treatment assists in the preparation for the repair of cleft lip, alveolar bone grafting, correction of malocclusions, and jaw surgery.

Typical orthodontic treatment planning may include, but not be limited to:

- Infant impressions, photographs, and imaging (3D soft tissue) in cases where infant orthopedics are under consideration.
- Dental films, cephalometric radiographs, photographs, and computer imaging should be utilized to evaluate and monitor dental and facial growth and development.
- For patients at risk of developing a malocclusion, or maxillary-mandibular discrepancy, diagnostic records including properly occluded dental study models (or digital models) should be collected at appropriate intervals.
- Dental care is necessary as primary dentition erupts. This care should include but not be limited to: dental examination, dental hygiene, preventative dental care, restorative dental care, and management of dental space. Before the primary dentition is completed, the skeletal and dental components should be evaluated to determine if a malocclusion is present or developing.
- Orthodontic treatment of malocclusion may be performed in the primary, mixed or permanent dentition,

or any combination according to patient-specific desired outcomes.
- Continuous, active orthodontic treatment from early mixed dentition to permanent dentition should be avoided. Each state of active orthodontic treatment may be followed by orthodontic retention and regular orthodontic observations. Orthodontic treatment and retention may extend into adulthood.
- Functional orthodontic appliances may be prescribed.
- Orthodontic treatment may be required in conjunction with surgical correction (and/or distraction osteogenesis) for correction of the facial difference. Collaboration and communication between the surgeon and orthodontist should precede all craniofacial surgical interventions as surgical intervention will have a direct impact on the growth and development of the dental and skeletal components.
- Individuals with congenitally missing teeth directly related to a history of cleft lip and/or palate may require fixed restorative bridgework or osseointegrated implants.
- Ongoing evaluation of dental hygiene and periodontal disease must be accomplished.
- In some patients, a prosthetic obturator of palatal fistulae may be necessary.
- In some patients, a prosthetic "speech appliance" may be necessary to treat velopharyngeal dysfunction.
- In addition to providing direct orthodontic care, the craniofacial orthodontist interacts with the patient and their family on a regular basis. This ongoing interaction allows the orthodontist to provide input to the cleft palate and/or craniofacial team regarding changes in the patient's behavior, sleep, academic performance, and social interactions.
- The craniofacial orthodontist may also be involved in assisting the family with referrals to a maxillofacial surgeon, periodontist, and prosthodontist.

Genetic/Dysmorphology Services

A comprehensive clinical genetic evaluation is a key component in the management of patients with congenital craniofacial differences and should include but not be limited to: (1) diagnosis, (2) recurrence risk counseling, (3) recommendations for medical management and surveillance studies based upon genetic diagnosis, and (4) counseling regarding prognosis.

- Indications for referral for a complete genetic evaluation include, but are not limited to: (a) positive family history, (b) prenatal growth deficiency, (c) unexplained postnatal growth deficiency, (d) developmental delay or intellectual disability, (e) associated major malformations and/or disorders, (f) associated minor malformations, (g) family request, and (h) recognized genetic diagnosis.
- Genetic testing may be recommended to determine diagnosis and/or confirm suspected clinical diagnosis.
- Complex syndromes involving craniofacial differences may not fully express clinical manifestations that can be recognized in the first years of life. Thus, genetic follow-up evaluations are necessary to continue the identification of the diagnoses and to use updated genetic testing.
- Genetic testing should be pursued to establish underlying diagnosis to allow for diagnosis-specific health surveillance, recommendations, and recurrence risk counseling for families (including adolescent/young adult with condition).
- Patients who are first seen by the team at later ages should also be evaluated by the geneticist.
- Prenatal ultrasound will often detect cleft lip with or without cleft palate. Isolated cleft palate is rarely identified by ultrasound. A timely referral to specialists experienced in diagnosis, management, and treatment of children with these and related conditions should be made. Additional maternal and fetal (imaging and invasive) testing may be recommended to assist with diagnosis and management of pregnancy.
- For families who live in areas which are geographically remote, the team should arrange for a referral to an accessible source where genetic services can be provided and should encourage the family to follow through on the referral.
- Personal genetic counseling should be offered to the maturing adolescent and young adult.

Nursing Care

Complex interdisciplinary management for individuals with congenital craniofacial differences requires a high level of ongoing coordination of services. The patient and family need appropriate information to understand the rationale for, and implications of, such management. Nursing assessment, interventions, and ongoing follow-up evaluations are integral to the long-term care needs of the child or individual with congenital craniofacial differences and family. Services for the patient and family include:

- Feeding assessments, interventional teaching, and follow-up of nutritional and growth assessments.
- Serving as role models of acceptance and nurturance for the patient and family including acceptance of cultural beliefs and cultural diversities.
- Preparation of patients and families for what to expect when either in-patient or out-patient surgical procedures are scheduled. Information should be provided on pre- and postoperative feeding, the rationale for the use of restraints, special positioning and equipment, wound care, skin management, activity restriction, anticipated outcome or general status immediately following surgery, and the necessity for, and timing of, postoperative examinations. Instructions must be given in a manner that assures understanding on the part of the family and other caregivers.

In addition to the direct nursing services provided to patients and families, members of the craniofacial team bear the responsibility for offering education to hospital and community nurses in feeding and other aspects of the special care required by children with craniofacial differences.

- Ongoing educational programs for, and consistent liaison with, the nursing staff of hospitals in the community, as well as in remote locations, to improve patient care and facilitate timely referrals for interdisciplinary patient management.
- Availability of education/guidance to hospital personnel involved in pre- and postoperative care of the patient undergoing surgery. These questions may involve use of arm restraints, feeding and hydration postoperatively, airway maintenance, pain management, surgical site protection, patient and family adjustment, and instructions for home care.

Otolaryngologic Care

Comprehensive care of children with cleft and craniofacial differences typically requires long-term monitoring and care of the ears, nose, and throat. Upper aerodigestive tract pathology is prevalent in these patients. Otolaryngologic care of the airway, speech, swallowing, and ears must be well coordinated with surgery, speech, and audiology. Otolaryngologic care begins at birth and can extend into adulthood.

Airway

- Sequential airway assessments beginning at birth are often required to evaluate structural and functional causes of airway difficulties. Such assessments may include but are not limited to: flexible and rigid endoscopy, radiologic studies, airflow studies, CT and MRI scans, and polysomnography.
- Upper airway obstruction may be due to but not limited to: facial skeletal insufficiency, soft tissue excess, nasal and\or septal difference, choanal stenosis/atresia, and laryngotracheal differences. Each of these possible disorders requires careful analysis and management. In newborns, failure to thrive and feeding problems are often airway related and may require coordination among otolaryngology, surgery, and speech-language pathology. In an older child, noisy breathing and obstructive sleep apnea may contribute to failure to thrive and/or academic difficulties.
- Airway management might include soft tissue reduction, such as tonsillectomy, reduction of turbinate, or tongue reduction.
- Adenoidectomy secondary to recurrent otitis media with effusion may be recommended. However, partial adenoidectomy is recommended in an effort to retain a portion of the adenoid to assist in velopharyngeal closure.
- Additional improvement in airway may be accomplished through nasal and septal reconstruction, addressing sinus dysfunction, and skeletal correction of deficient mandible and/or maxilla.
- When required, laryngotracheal procedures, including, but not limited to, tracheotomy or supraglottoplasty, might be indicated if the individual experiences signs of airway obstruction at the laryngeal level. The impact of secondary speech procedures (i.e., pharyngoplasty, pharyngeal flap) on the airway must also be considered.

Ears and Hearing

- The ears should be evaluated on a regular basis, beginning with a physical examination of the ears in the initial months of life.
- Results of the newborn hearing screen should be obtained and discussed with the family.
- Eustachian tube function must be evaluated on an ongoing basis to evaluate possible dysfunction in the middle ear.
- Early detection and treatment of otitis media with and without effusion is mandatory, as hearing loss can impact communication.
- Treatment of middle ear disease may include but not be limited to: systemic and or topical antibiotics, insertion and/or removal of tympanostomy tubes, tympanoplasties, removal of cholesteatomas, mastoidectomies, and ossicular reconstruction.
- Microtia and aural atresia reconstruction require close coordination between surgical and/or prosthetic treatment and aural rehabilitation.

Pediatric Care

Pediatric care provided within the context of the team is fundamental in assuring that the health needs of the child with craniofacial differences are identified and appropriately treated. Pediatric team care ideally begins prenatally and continues until the patient's care is successfully transitioned to adult providers. Pediatricians, nurse practitioners, and geneticists often serve as the pediatric provider on the team. This provider partners with the patient, family, primary care provider, and team members to optimize the patient's health. The goals of the pediatric team care provider include but are not limited to:

- Ensure that each child has a primary care provider who functions as an external member of the team.
- Identify the clinical diagnosis for the patient's health concern(s). Establishing a diagnosis may require variable combinations of laboratory, imaging, and/or consultant evaluations. Accurate diagnoses are critical to ensure appropriate patient care.
- Provide the patient, family, community, and team providers with information regarding the patient's diagnosis. Information should include but not be limited to: etiology (if known), inheritance (recurrence risk for patient and family), and natural history (including

associated health concerns). The pediatric provider will recommend genetic consultation when indicated.

- Monitor the patient's health status and initiate evaluation and treatment of health problems directly related to the specific craniofacial condition (e.g., cleft palate), diagnosis (e.g., 22q11.2DS), family history (e.g., parent with thrombosis), patient symptoms (e.g., sleep-disordered breathing), and physical exam findings (e.g., murmur). Provide patient, family, community provider, and team members with recommendations for age-specific health surveillance based upon the patient's diagnosis. Partner with the community provider to establish an individualized health surveillance plan.
- Provide the patient, family, community provider, and team members with diagnosis-specific health risk precautions, such as but not limited to: spine at risk, medication risk, or potential for adrenal insufficiency.
- Partner with craniofacial team members and the community physician to advocate for appropriate community evaluations, therapies (e.g., Birth to Three), and support (e.g., IEP).
- Monitor children for growth failure, delayed development, abuse and neglect, or other significant health concerns. When special needs are identified, referral to appropriate specialists should be initiated in cooperation with the primary care provider.
- Assess parental understanding of the child's health needs, and address questions regarding their child's health issues.
- Evaluate the child's health prior to planned surgical procedures, and provide recommendations regarding readiness for both surgical and nonsurgical interventions.

Psychological and Social Services

The accomplishment of the goals of treatment of the patient with craniofacial differences requires periodic assessment of the psychosocial needs of both the patient and the family. The psychosocial interviewer may come from the ranks of professionals such as those in social work, psychology, pediatrics, nursing, and psychiatry. Standardized assessment of neurodevelopmental functioning of infants, toddlers, and preschoolers may be performed by qualified professionals. However, for school-aged children, standardized psychological tests must be administered and interpreted under the supervision of a licensed psychologist (or other licensed professional who is trained to administer and interpret these tests), preferably a person familiar with craniofacial differences and related speech and hearing disorders.

- Psychosocial screening interviews should be conducted periodically to assess parental competence and nurturance, child management skills, parent-child relationships, and the emotional and behavioral adjustment of the child. This screening should begin in infancy and continue throughout young adulthood. Psychosocial screening should be conducted to assess the individual's emotional readiness for early surgical intervention. Parents and youth with craniofacial differences should receive guidance regarding topics to include but not be limited to: behavior management, teasing, rejection by other family members, public attitudes, fear of and expectations from surgical procedures, and emotional adaptation to treatment. If concerns are identified, each family should receive or be referred for comprehensive psychosocial evaluation, and, as appropriate, intervention.
- The high rate of learning disorders in children with craniofacial conditions requires that each child be screened for potential neurodevelopmental and learning disorders. When problems are suspected or identified in these areas, the child should receive or be referred for formal developmental/cognitive evaluations and intervention as needed. When appropriate, referral for vocational training should be provided to adolescents.
- Information about learning performance should be obtained periodically. If neurodevelopmental and/or learning disorder evaluations/intervention services are provided in the child's community, these services should be reviewed and monitored by the team on an ongoing basis.
- Families of children with craniofacial differences may benefit from contacts with other families. The team should facilitate such contact through support groups, networking, and other social skill-building opportunities.
- As they mature, individuals should be given information about their craniofacial difference and should be permitted and encouraged to become active participants in treatment planning. All care providers should be sensitive to how treatment discussions can be perceived by children and should do everything possible to ensure that the child understands the treatment plan as much as possible.
- Team care should include preparation for the support and transition of the young adult to adult craniofacial care.

Speech-Language Pathology Services

Children with cleft palate and craniofacial differences are at risk for communication disorders. Careful assessment of speech and language skills is essential in determining management (e.g., surgical, dental, speech-language therapy), monitoring progress, and evaluating treatment outcomes. Speech-language evaluations should occur often enough to ensure appropriate documentation of each child's current communication skills, their communication progress, and to develop appropriate recommendations for intervention based on the individual's age and needs.

- Speech-language pathology services should include ongoing evaluations of language development. These evaluations should begin prior to palate repair.
- Speech evaluations for a child with a craniofacial difference should be conducted on an annual basis and/or per

team request up to six years of age. Additional speech evaluations should be conducted if there are concerns of language disorder, articulation disorder, or resonance imbalance.

- If it is determined that communication skills are not at an age or developmentally appropriate level, or if early speech productions are deviant, a referral should be made to a qualified speech-language pathologist in the community. This may include an early childhood intervention program that includes speech-language pathology services.
- For individuals present with communication disorders, and for those in which the basis for continuing velopharyngeal dysfunction cannot be definitively determined, reevaluations should take place as often as deemed necessary by members of the interdisciplinary team in consultation with local care providers.
- Evaluations of communication conducted as a part of a team visit should include, but not be limited to: language development, articulation development, and perceptual assessment of resonance and voice.
- If articulation is deviant and characterized by maladaptive compensatory misarticulation errors associated with cleft palate, speech therapy may result in positive changes in velopharyngeal closure.
- Speech evaluations are necessary pre- and post-treatment to determine candidacy for, and outcomes of, surgical, behavioral, and/or prosthetic management of the velopharyngeal system.
- For patients with craniofacial differences who are candidates for orthognathic surgery, pre- and postoperative perceptual speech evaluations are necessary.
- Instrumental assessment of velopharyngeal function is required for all patients with resonance disorders and/or audible nasal air emission. Instrumental assessment procedures may include but not be limited to: imaging (multiview videofluoroscopy, nasopharyngoscopy), aerodynamic (pressure flow), acoustic (nasometry), and speech recordings. These procedures may be done by the team speech-language pathologist or in collaboration with other team members or colleagues (e.g., plastic surgeon, otolaryngologist, radiologist).
- If a voice difference is present, a referral should be made to an otolaryngologist and a recommendation for direct laryngoscopy. This is necessary prior to initiating voice therapy.
- Speech and/or language therapy may be needed for some patients with cleft and craniofacial differences. The need for treatment will be based on the results of a formal assessment.
- Biofeedback therapy, including, but not limited to, nasopharyngoscopy, acoustic (nasometry) or pressure flow studies, may be useful in treating some patients with velopharyngeal dysfunction.
- Blowing exercises and oral motor therapy are not effective in treating velopharyngeal dysfunction.
- In addition to the direct speech services provided to patients, team speech-language pathologists should collaborate with and provide guidance to community providers to implement appropriate treatment plans.

Quality Management

The quality of care for patients with craniofacial differences and related disorders must be carefully monitored by the team providing diagnosis, treatment planning, and treatment services. This requires (1) longitudinal assessments of the outcomes of treatment, (2) periodic team review of the clinical outcome data, and (3) team adaptation of treatment procedures when clinical outcome assessments do not reach referenced criteria.

Revisions of Clinical Practices

The clinical practices presented in this document reflect current knowledge and experience. Changes in these practices will be guided by advances in technology and research, including data on clinical outcome. Thus, timely review and revision of this document will be necessary.

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Ann W. Kummer, Ph.D., C.C.C.-S.L.P.
Speech-Language Pathology

William R. Laney, D.M.D., M.S.
Prosthodontics/Prosthetics

Guy L. Lanzi, D.M.D.
Oral/Maxillofacial Surgery

Judith A. LeDuc, M.A.
Speech-Language Pathology

Shirley S. Maxey, B.S.
Nursing

Mohammad Mazaheri, D.D.S.
Prosthodontics/Prosthetics

Maureen McGovern, M.S.W.
Social Work

Hughlett L. Morris, Ph.D.
Speech-Language Pathology

John B. Mulliken, M.D.
Plastic Surgery

Ian R. Munro, M.D.
Plastic Surgery

Mary E. Nelson, B.S.N., R.N.
Nursing

Snehlata Oberoi, B.D.S., M.D.S., D.D.S.
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William H. Olin, D.D.S., M.S.
Orthodontics

Douglas K. Ousterhout, D.D.S., M.D.
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Jack L. Paradise, M.D.
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Patrick S. Pasquiriello, Jr., M.D.
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Pravin K. Patel, M.D.
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John A. Persing, M.D.
Plastic Surgery

William P. Potsic, M.D.
Otolaryngology

Cheryl S. Reid, M.D.
Genetics

Jennifer L. Rhodes, M.D.
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Morton S. Rosen, D.D.S.
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Dennis M. Ruscello, Ph.D.
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Craig W. Senders, M.D.
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* Denotes an individual who has a craniofacial difference or is the parent of a child with a craniofacial difference.

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