## CRANIOFACIAL ANOMALIES RECOMMENDATION TO GO TO HOUSE OF DELEGATES

There is wide disparity with how states mandate insurance coverage for treatment of craniofacial anomalies (CFA). Unfortunately, a lack of rules and requirements often leave CFA individuals and their families uncovered by insurance for extensive and expensive treatment protocols to reconstruct and restore affected children. The AAO House of Delegates will discuss a proposed AAO policy to address this problem.

Craniofacial anomalies (CFA) are congenital abnormalities in the bone or soft tissue of the face or head and comprise a wide range of heterogeneous conditions with many associated syndromes. Some CFA and their associated syndromes are relatively common, such as cleft lip without cleft palate, which has an estimated prevalence of 1 in 940 newborn babies<sup>1</sup>. Patients born with a CFA often will present with multiple auxiliary syndromes associated with the initial CFA. For example, about 350 different syndromes are associated with facial clefts, including hypodontia, malocclusion and airway obstruction. Babies and children with CFAs will have difficulty eating, including regurgitation and aspiration, ear infections, hearing loss, permanent speech impediments, gross jaw deformities of various types and a broad range of dental related challenges – all of which are justifications for unavoidable surgical management.

Cleft lip repair is typically performed when a child is 6 to 12 weeks old and may require multiple surgeries depending on the extent of repair needed. Cleft palate treatment is more extensive and requires an interdisciplinary team approach over the course of 18 years. Initial therapies create a functional palate, reduce the chances that fluid will develop in the middle ears, and aid in the proper development of the teeth and facial bones. Later treatments are performed to account for the child's growth and development to ensure continued proper function as the child matures.

The multistage therapeutic approach can result in significant improvement in an individual's quality of life, ability to eat, breathe and talk. Therapeutic intervention may be required early in life but often will be delayed until the patient has developed to a point that further correction will be optimized. As a member of the team of multispecialty providers, orthodontists play an important role in the carefully orchestrated, multistage correctional approach for CFA patients. The goal is to restore the jaw and facial structures, leading to normal function and appearance.

Medically necessary treatment must consider function, appearance, nutrition, speech, hearing, and emotional and psychological development. While insurance carriers generally provide coverage for early treatment of CFA, procedures performed later in a child's life are frequently

denied because of a "lack of medical necessity" or being deemed "cosmetic" in nature. All therapeutic procedures related to CFA are performed not for esthetics but for reconstructive purposes to address extensive sequelae resulting from the congenital condition. Frequently denied treatments include the placement of dental implants, orthodontics and orthognathic surgery – all of which are necessary to restore function due to the initial oral cleft condition.

Currently, only 18 states mandate insurance coverage for treating CFA<sup>2</sup>. Several states stipulate orthodontic coverage but do not stipulate any standard of care. Similarly, CFA treatment is determined to be, 'medically necessary' in some states but definitions regarding 'medical necessity' vary widely. While attempts have been made as recently as 2007 to stipulate care coverage for CFA at the U.S. federal level, to date no bill has passed Congress. Diverse state laws, rules and requirements often leave CFA individuals and their families uncovered by insurance for most necessary therapies to reconstruct and restore CFA individuals.

To address the problem of insurance coverage for Craniofacial Anomalies the AAO Council on Orthodontic Health Care recommends the following:

For the purpose of third party reimbursement, the AAO considers serial reconstructive, orthodontic and restorative therapies to be medically necessary treatment for craniofacial anomalies (CFA) to ensure a reasonable quality of life for affected individuals. Coverage should extend at least until age 26.

Furthermore, the AAO supports legislation stipulating that insurers recognize the sequential nature of reconstructive and restorative therapy for CFA which requires ongoing coverage for all aspects of the treatment plan.

Some of the background information comes from the AAOMS white paper <u>Craniofacial</u> <u>Anomalies</u> - edited)

## References:

- 1.Parker SE, Mai CT, Canfield MA, Rickard R, Wang Y, Meyer RE, Anderson P, Mason CA, Collins JS, Kirby RS, Correa A; for the National Birth Defects Prevention Network. Updated national birth prevalence estimates for selected birth defects in the United States, 2004-2006. Birth Defects Research (Part A): Clinical and Molecular Teratology 2010;88:1008-16.
- 2. Primer on State Statutory Mandates of Third- Party Orthodontic Coverage of Cleft Palate and Craniofacial Care in the United States, Unpublished article