Dental Health in Individuals with CdLS

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Families with a child with CdLS had the option to have a consult with Pediatric Dentistry during the National Family Conference. Ideally, they should all have a pediatric dentist. The youngest child seen at Conference is usually around 12 months; the oldest has been over 50 years. Reasons for choosing a dental consult include questions about care for the teeth, "adult" vs. "baby" teeth, braces, sedation for dental work and accidents involving teeth.

There are some common questions that arise during the dental consults. Do my child's teeth appear normal? When will the baby teeth fall out and the adult teeth come in? Should the baby teeth be pulled to make room for the adult teeth? Often in CdLS there can be missing or absent teeth and all of the teeth take a long time to erupt (come in). The primary (baby) teeth have delayed eruption and often the first tooth does not come in until after 12 months. A pediatric dentist should be established when the first tooth erupts or around 12 months of age. The pediatric dentist will review oral hygiene and diet recommendations including avoiding juices, especially apple, and nothing to eat or drink after brushing at bedtime.

Permanent (adult) teeth take a long time to erupt as well. It is helpful to have a panorex x-ray around 6-7 years of age, to see if any teeth are missing and the positions of the adult teeth. Because the permanent teeth take a long time to erupt, there is no benefit to having the primary teeth pulled. This would only create a space that would take a long time to fill in. I recently received a phone call from a pediatric dentist of a child I had seen at Conference who wanted to sedate the child in order to pull out the remaining primary teeth. I had to explain that this is not necessarily beneficial for the child due to delayed eruption. Also, it would put the child at risk with anesthesia.

Other common questions: How often should the child's teeth be brushed? Is there a particular toothbrush recommended? Do I need to floss? How often should the child be seen by the dentist? All individuals with CdLS should have their teeth brushed (or brush themselves) at least twice a day. An electric toothbrush can be very well tolerated, especially if the child enjoys vibrations. The parent should always help brush a child's teeth after the child has attempted to brush them. When small, the child should be gently held to brush the teeth. A Collis Curve toothbrush can be helpful since it brushes all sides of the teeth at once (can be purchased online). Toothpaste with fluoride is always recommended. Flossing should be done whenever possible using floss picks. Dental cleaning should be done twice a year, and when older, three times a year to prevent periodontal disease if able to be managed in the office. If the child or adult is not cooperative, cleanings may need to be done in the hospital under sedation every 3-5 years.

Orthodontics has been tolerated by some children with CdLS. There has to be cooperation to be able to hold still, not only for x-rays and impressions, but also for regular visits and adjustments. Those that have had braces have generally had good results. It should be remembered that this is an optional treatment. Finally, accidents involving the teeth should be evaluated in the context of the harm to the child. A phone call to the child's dentist can help guide management.

This year at the Scientific Symposium, I presented a recent dental observation that I have seen only in children with CdLS around 12 years old. Below the lower front central incisors, there is an attachment from the inside of the lower lip to the gingiva (inner gum tissue) called the frenum. In some pre-teens and teenagers with CdLS, this frenum becomes tight and pulls the gingival tissues down on the front of the teeth, exposing the bone underneath. This creates a situation that could lead to gingival recession and/or bone loss and potential future tooth loss. I have participated in repairing this frenum with a periodontist. If this is seen, a referral to an oral surgeon or periodontist for a frenectomy (removal of the frenum) leads to appropriate care. Anesthesia is required, and whenever a child or adult with CdLS receives anesthesia, special attention has to be made to the small chin and jaw. Also, avoid using Versed (Midazolem) as an anesthetic agent.

There are great guidelines and recommendations for anesthesia on the CdLS Foundation website. I highly recommend that any parent whose child will undergo anesthesia share these articles with their anesthesiologist prior to any procedure: http://www.cdlsusa.org/docs/anesthesia-and-cdls.pdf and http://www.cdlsusa.org/docs/publications/anesthesia/BestPracticesPhysicians-Anesthetic.pdf. We are also always available for dental questions through the Ask the Experts section of on the CdLS Foundation website.