

INFORMATION ABOUT CHOOSING A CLEFT PALATE OR CRANIOFACIAL TEAM

Throughout the United States there are many qualified health professionals caring for children with cleft lip and palate as well as other craniofacial anomalies. However, because these children frequently require a variety of services that need to be provided in a coordinated manner over a period of years, you may want to search for an interdisciplinary team of specialists. The primary purpose of the team approach is to assure that all of your child's health care providers are working together to provide the best possible care. Here are some points to consider when selecting a team:

1. The Number of Different Specialists Who Participate on the Team

The more specialists participating on the team, the more likely every aspect of treatment can be considered during the team evaluation. 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 the services required by its patients, team members are responsible for making appropriate referrals and for communicating with those to whom patients are referred. This arrangement will allow treatment plans to be coordinated and carried out in an efficient manner. Although not all patients will need each type of specialist, the team may include:

- a surgeon (such as a plastic surgeon, an oral/maxillofacial surgeon, a craniofacial surgeon, or a neurosurgeon);
- a pediatric dentist or other dental specialist (e.g., a prosthodontist, who makes prosthetic devices for the mouth);
- an orthodontist (to straighten the teeth and align the jaws);
- a speech-language pathologist (to assess not only speech but also feeding problems);
- an audiologist (to assess hearing);
- a geneticist (to screen patients for craniofacial syndromes and help parents and adult patients understand the chances of having more children with these conditions);
- a nurse (to help with feeding problems and provide ongoing supervision of the child's health);
- an otolaryngologist (an ear nose and throat doctor, or ENT);
- a pediatrician (to monitor overall health and development);

- a psychologist, social worker, or other mental health specialist (to support the family and screen for behavioral and developmental concerns);
- an ophthalmologist (an eye doctor for children whose vision is affected by a syndrome);
- and other necessary specialists who treat specific aspects of complex craniofacial anomalies.

When these specialists work together, and with the family, as an interdisciplinary team, treatment goals can be individualized for each child, and parents and health care providers can make the best choices for treatment by consulting with each other. Because growth is a significant factor in the ultimate outcome of treatment, the child must be assessed thoroughly and regularly by the team until young adulthood.

The Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies document summarizes the current guidelines for team care endorsed by the American Cleft Palate-Craniofacial Association. By adhering to these guidelines, teams are promoting the best possible outcome for children born with clefts or other craniofacial birth defects.

2. Qualifications of the Individual Members of the Team

All the professionals on the team should be fully trained and appropriately certified and licensed. This issue may impact your insurance coverage, as well as the quality of care the team can deliver. You can check with each professional's specialty organization for this information. For example, the American Society of Plastic Surgeons certifies plastic surgeons, and the American Speech-Language Hearing Association certifies speech pathologists.

3. Experience of the Team

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 cleft lip/palate and other craniofacial anomalies. You should ask how often the team meets and approximately how many patients are seen at each meeting. You may also want to try to determine how long this group

of professionals has been working together and how much experience the various individual professionals have had. It is perfectly acceptable for you to ask a surgeon how often he/she performs the specific surgery your child needs.

4. Location of the Team

The distance of the team from your home may NOT be an important consideration in choosing a team. In general, the team will be seeing your child only periodically throughout his/her growing years. Usually routine treatment such as general dental care, orthodontics, speech therapy, and pediatric care will be provided by professionals in your own community who will be in regular contact with the professionals on the team. Your travel to a team will usually be limited to several trips a year or even once a year.

5. Affiliation of the Team and Its Members

You may want to ask if the team is listed with the American Cleft Palate-Craniofacial Association (ACPA) and how many of the individual members of the team are also members of ACPA. Staying current with recent developments in the field is one sign of a conscientious and concerned health care professional. You may also want to determine whether the team has any relationship to an established hospital or to a medical school or university. Facilities for diagnostic studies and treatment are often better with such an affiliation.

6. Communication with the Team

Your child may require care over a period of years, so you want to make sure you are comfortable communicating and working with the members of the team. Treatment recommendations should be communicated to you in writing as well as in face-to-face discussion. The team should assist you in locating parent-patient support groups and any other services that are either not provided by the team itself or are better provided at the community level.



For further information on cleft lip and palate, or for a referral to a cleft palate/craniofacial team, please contact:

American Cleft Palate-Craniofacial Association
1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514
919.933.9044
www.cleftline.org
info@acpa-cpf.org