Transforming Lives:
The Difference a Craniofacial Care Team Can Make

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Welcome and Introductions

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Presentation

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How the Comprehensive Care Team Concept Evolved

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Why does my child need to be cared for by a “team”??

• It is not just about having “a surgery”
• Cleft and craniofacial conditions are complex – requiring the services of multiple clinicians
• There may be other needs/challenges – breathing, hearing, vision, nutrition, dental health, psychosocial issues

Management of the child with a cleft/craniofacial condition often requires treatment throughout their childhood/adolescence
• The team approach to care is efficient
• Parental/family involvement is an important part of the team concept
• It is a journey...
American Cleft Palate-Craniofacial Association

- A professional organization – dedicated to supporting the comprehensive care of patients/families
- Members are from all specialties, nationally/internationally
- A major goal – to provide education/resources to both clinicians and patients/families
- “The Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Differences was published in 1993 and last updated in 2018.
- www.acpa-cpf.org

Parameters for Evaluation/Treatment

Fundamental Principles:
- “Management of patients with craniofacial differences is best provided by an interdisciplinary team of specialists.”
- “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.”
## Cleft Lip/Palate Team

- Plastic Surgeon
- Orthodontist
- Speech Pathologist
- Audiologist
- Geneticist
- Medical Photographer
- Nutritionist
- Oral/Maxillofacial Surgeon
- Otolaryngologist
- Pediatric Dentist
- Pediatrician
- Psychologist
- Prosthodontist
- RN/Nurse Practitioner
- Social Worker
- Team Coordinator

## Craniofacial Team

- Plastic Surgeon
- **Neurosurgeon**
- Orthodontist
- Audiologist
- Geneticist
- Medical Photographer
- Nutritionist
- **Ophthalmologist**
- Oral/Maxillofacial Surgeon
- Otolaryngologist
- Pediatric Dentist
- Pediatrician
- Psychologist
- Prosthodontist
- RN/Nurse Practitioner
- Social Worker
- Speech Pathologist
- Team Coordinator
How Do I Start to Find The Right Cleft/Craniofacial Team?

- Referrals from Pediatrician, Ob/Gyn, Geneticist
- Personal Referrals – Friends/Family Members/Co-workers
- American Cleft Palate-Craniofacial Association (acpa-cpf.org) – Team Membership Directory
- Internet Groups – who are they recommending in your area? A few warnings…

Questions – Make a List Before Meeting the Team

- Do you have separate cleft and craniofacial teams?
- How long has your team been together?
- How often do your teams meet?
- Who are the members of your team?
Questions – Make a List Before Meeting the Team (Cont.)

• Which team members will be present at the meeting?
• Are all team members located in the same physical space?
• Does your team participate in our insurance?
• Is your team listed in the ACPA Membership Directory?

Questions to Ask During the Team Meeting

• Can you explain what the treatment might involve over the years? How many surgeries might s/he possibly need?
• How many patients with our child’s condition do you care for every year? The first operation sets the course…
• May we see pre and postoperative photos of other children with this condition who your team has cared for?
Questions to Ask During the Team Meeting

• May we speak with other parents whose child has the same condition?
• Has your team published about the work that you have done with children with our child’s condition? If so, could you give us some of the references?
• Does your team have a support group?

For more information on craniofacial care teams visit [www.myface.org/craniofacial-care-teams/](http://www.myface.org/craniofacial-care-teams/)
For more information on craniofacial care centers visit [www.myface.org/craniofacial-care-centers/](http://www.myface.org/craniofacial-care-centers/)

**Question & Answer**

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Closing Remarks

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For additional information and resources visit myFace.org

Or email us at info@myface.org