





Transforming Lives: The Difference a Craniofacial Care Team Can Make

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Welcome and Introductions



Stephanie Paul Executive Director myFace

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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







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Why does my child need to be cared for by a "team"?? (Cont.)



- 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...

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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

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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."

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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

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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

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How Do I Start to Find The Right Cleft/Craniofacial Team?

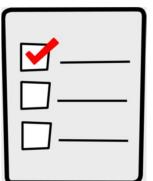
- Referrals from Pediatrician, Ob/Gyn, Geneticist
- Personal Referrals Friends/Family Members/Co-workers
- American Cleft Palate-Craniofacial Association (acpa-cpf.org) Team Membership Directory
- Visit myFace <u>www.myface.org/craniofacial-care-teams/</u>
- Internet Groups who are they recommending in your area? A few warnings…

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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?



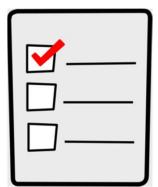
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Questions - Make a List Before Meeting the Team (Cont.)

- 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?



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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?

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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?

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For more information on craniofacial care teams visit www.myface.org/craniofacial-care-teams/



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For more information on craniofacial care centers visit www.myface.org/craniofacial-care-centers/



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Question & Answer



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Closing Remarks



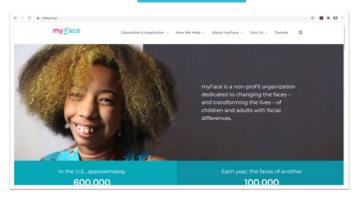
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For additional information and resources visit myFace.org



Or email us at info@myface.org

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Thank You