Welcome and Introductions

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Presentation

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Aims

• Highlight CL/P Background Information
• Discuss Approach to Prenatal Diagnosis
• Review Key Concepts for Prenatal Counseling
• Emphasize the Impact on Post-Natal Care
• Introduce Concept of Community Building
Cleft Lip and Palate Background

- Very Common → 1/700 live births
- More common in males and on the left side
- 67% CL/P (46% combined, 21% CL alone)
- 33% CP alone

Cleft Lip and Palate Background

- Majority of Children will have Isolated CL/P
- 29% have additional Congenital Anomalies
- Some Children Will have a Craniofacial Syndrome
Cleft Lip and Palate Etiology

- Multi-factorial process
- Environmental factors → Phenytonin, ETOH, Accutane, Corticosteroids and Tobacco
- Folic Acid supplementation protective against Cleft Lip
- Isolated Cleft Lip thought to be sporadic

Cleft Lip and Palate Etiology

- Cleft Lip occurs during the 4–5th week of gestation
  - Failure of Fusion of Embryologic Facial Processes
- Cleft Palate occurs during the 6–8th week of gestation
  - Failure of Fusion of the embryologic Maxillary processes
Prenatal Diagnosis

Thirty Years of Prenatal Cleft Diagnosis: What Have We Learned?

Jordan P. Steinberg, M.D., Ph.D.
Amir K. Goula, M.D.
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Summary: Prenatal ultrasound diagnosis of cleft lip with or without cleft palate has received little attention in the plastic surgery literature despite its initial descriptions more than 30 years ago. With more families presenting in the prenatal period, it is critical for plastic surgeons to understand the techniques in use to diagnose the prenatal cleft lips as well as their associated limitations. Moreover, it is incumbent on surgeons to understand the implications of the diagnosis as well as how to appropriately counsel affected families, including how to handle questions pertaining to termination. A comprehensive review was initiated to educate plastic surgeons with respect to these aims. The following points may be inferred: (1) Based on the rates of associated anomalies in low-risk screened populations, as opposed to the high-risk groups in previous reports, potentially detected clefts do not appear statistically different from historically described cohorts; (2) the absence of structural anomalies, chromosomal anomalies in postnatally detected cleft patients are rare; (3) ultrasound detection rates are highly variable across studies (10 percent to 90 percent); (4) reporting error ranges from 10 percent to 90 percent and largely relate to characterization of the secondary palate; (5) accuracy is improving with the adoption of newer technologies, including three-dimensional ultrasound; and (6) prenatal diagnosis enables counseling and a sense of preparedness for the majority of affected families and only rarely results in termination for isolated clefts. (Plast. Reconstr. Surg. 136: 286, 2015.)

- Diagnosis Often Made During Anatomy Scan (16–22 wks.)
- Greater than 90% of Clefts can be detected Prenatally
- Detection Affected by: Anatomy, Imaging Modality
- Cleft Lip Easier to see on Ultrasound than Cleft Palate

Common Prenatal Questions

- How Did the Cleft Occur?
- Why Did the Cleft Occur?
- What Do I do Next?
- What will my Child Look Like?
- How is My Child Going to Eat
- How is My Child Going to Speak
- What Surgeries will my Child Need
Information vs Misinformation

Psychosocial and socioeconomically aspects of mothers having a child with cleft lip and/or palate (CL/P): a pilot-study during the first year of life

Konstanze Scheller 1, Jasmin Urich 1, Christian Scheller 1, Stephan Watzke 2

Fig. 2: First medical information. Most mothers were informed about the consequences of the diagnosis of a cleft lip and palate (CL/P) by a gynaecologist or a maxillofacial surgeon (a). The “bad” information (b), the access of medical information after diagnosis (c) and the predominant feelings (red bar) and emotions (grey bar) at diagnosis were analysed in detail (d).

Prenatal Counseling Roadmap

- Comprehensive Prenatal Diagnostic Work-up
- Introduction to Comprehensive Cleft Care
  - Timeline, Multi-disciplinary care, Cleft resources
- Demystifying the Cleft
- Cleft Challenges and Preparation
- Building Cleft Community

Comprehensive Diagnostic Work-up

- Prenatal Imaging → 2D/3D → Fetal MRI
- Prenatal Genetic Testing and Counseling
- Fetal Echo Cardiogram
- Maternal Fetal Medicine Consult
Comprehensive Diagnostic Work-up

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- Prenatal Genetic Testing and Counseling
- Fetal Echo Cardiogram
- Maternal Fetal Medicine Consult

Coordination of the Fetal Medicine Institute and the Cleft and Craniofacial Center: Application to Early Management of Infants With Cleft Lip and Palate

Kenneth L. Fox, MD,1 Çara K. Black, BA,2 Esperanza Marentes-Rivas, MD,1 Dorothy I. Babas, MD,1 Eva Rubio, MD3 Anna R. Black, MD,1 Chelsea Robinson, BS3 and Albert K. Oh, MD3

Background/Purpose: The primary objective of this study was to describe the authors’ experience at the Children’s National Health System with the coordination of the Fetal Medicine Institute and the Cleft and Craniofacial Center. This collaboration highlights the importance of prenatal diagnosis of cleft anomalies and its potential impact on patient outcomes.

Methods: A retrospective review of the authors’ experience with 74 patients referred for potential cleft anomalies. The authors performed ultrasound imaging, and follow-up prenatal evaluations included detailed sonographic and 3D imaging of the fetal anatomy. Clinical and radiological data were reviewed to evaluate the accuracy and completeness of the prenatal diagnosis of cleft anomalies.

Results: Sensitivity and specificity for isolated unilateral cleft lip were 89% and 100%, respectively, and cleft lip and palate, sensitivity and specificity were 32% and 99%, respectively, for bilateral cleft lip and palate, sensitivity and specificity were 97% and 90%, respectively. Initial postnatal evaluation by the cleft team was performed at an average age of 23 days after birth. All patients who were candidates for presurgical orthodontia were treated at an appropriate early age (mean 66.5 days).

Conclusions: Coordinated prenatal evaluation of patients with cleft lip/palate by multidisciplinary centers plays an important role in the care of these complex patients. The results of the authors’ study demonstrated high sensitivity and specificity for the prenatal diagnosis of cleft lip/palate, leading to timely postnatal evaluation and treatment.
Compressive Cleft Care

Cleft Lip/Palate Treatment Timeline

NOTE: Treatment timeline provided includes approximate time frames and may vary by patient.
Cleft and Craniofacial Team

The Multidisciplinary Cleft and Craniofacial Team

Many specialists are needed to provide the expert consultation and skillful care required to diminish the problems of craniofacial disfigurement. The following healthcare professionals work as a team to provide your child with the best possible care:

- audiologists (hearing specialists)
- genetic counselors
- neurosurgeons
- nurse coordinators
- occupational and physical therapists
- ophthalmologists
- oral and maxillofacial surgeons
- orthodontists
- otolaryngologists (ear-nose-throat specialists)
- pediatric dentists
- pediatricians
- plastic and craniofacial surgeons
- social workers
- speech and language specialists

Cleft Lip and Palate Challenges

A study into weight gain in infants with cleft lip/palate

Figure 1: Combined group percentile position at birth

Table 2: Mean percentiles of study group compared with general population

<table>
<thead>
<tr>
<th>Number</th>
<th>Mean percentile at birth (SD)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combined group</td>
<td>187</td>
<td>42.7 (12.2)</td>
</tr>
<tr>
<td>UCLP</td>
<td>43</td>
<td>44.1 (12.8)</td>
</tr>
<tr>
<td>RCLP</td>
<td>85</td>
<td>38.6 (18.6)</td>
</tr>
<tr>
<td>ICP</td>
<td>92</td>
<td>45.4 (20.6)</td>
</tr>
<tr>
<td>UCLP</td>
<td>36</td>
<td>44.1 (13.4)</td>
</tr>
<tr>
<td>RCLP</td>
<td>15</td>
<td>45.9 (17.2)</td>
</tr>
<tr>
<td>ICP</td>
<td>54</td>
<td>4.8 (12.4)</td>
</tr>
<tr>
<td>Syndromic</td>
<td>43</td>
<td>38.3 (29.7)</td>
</tr>
<tr>
<td>KS</td>
<td>7</td>
<td>40.0 (48.5)</td>
</tr>
<tr>
<td>UCLP</td>
<td>1</td>
<td>43.4 (30.0)</td>
</tr>
<tr>
<td>RCLP</td>
<td>5</td>
<td>31.4 (26.9)</td>
</tr>
<tr>
<td>ICP</td>
<td>31</td>
<td>28.2 (28.7)</td>
</tr>
</tbody>
</table>

*p value calculated using One sample t test. *significant at 0.05 level
Treatment of Cleft Lip and Palate

Specialized Bottles for CLP
Dr. Brown Specialty Feeder

Monitored Feeding Program
Incidence of Gastroesophageal Reflux Disease in Children With Cleft Lip and Palate and an Evaluation of Its Impact on Weight Gain

Ishani D. Premaratne, BA, Nicholas Brownstone, MD, Philip Lofti, MD, and Thomas A. Imahiyerobo, MD, FACS, FAAP

Abstract: Patients with cleft lip and/or palate have higher rates of failure to thrive (FTT), decreased growth, and more often experience feeding difficulties as compared with the general pediatric population (J Child Health Care. 2014;8:72-85). Although insufficient nourishing, excessive air intake, and incorrect feeding methods have been established in the literature, the role of gastroesophageal reflux disease (GERD) as a contributing factor in cleft patients has not been thoroughly examined. Recently, there is a paucity of literature analyzing the incidence and effect of GERD in cleft children. Furthermore, no studies have evaluated the effect of GERD therapy on improvement of weight gain and FTT in cleft patients. The purpose of this retrospective review was to identify the incidence of GERD in the orofacial cleft population and to see if appropriate treatment was effective in improving weight gain. Fifty patients with cleft lip and/or palate were identified from a single surgeon’s experience at a large academic medical center from 2015 to 2019. The data show that a significantly higher percentage of patients with cleft lip or palate have clinical evidence of GERD, which required treatment as compared to published reports of less than 1% in the non-cleft population. The data also suggest that the patients diagnosed with GERD who received pharmacologic treatment showed improved weight gain as compared to those who did not. Given our findings, the diagnosis of GERD should be considered in orofacial cleft patients exhibiting signs of difficulty eating or those with FTT. The early diagnosis and treatment of GERD in patients with orofacial cleft may improve weight gain.

Key Words: cleft lip and palate, gastrointestinal reflux disease, failure to thrive

Three-Dimensional Assessment of Facial Appearance Following Surgical Repair of Unilateral Cleft Lip and Palate


Figure 1: Comparison of 3D facial model with surgical correction

Figure 6: Average root asymmetry scores for landmarks across different facial regions.

Figure 7: Landmark-based asymmetry scores for different facial components.
Pre-surgical Nasal Molding

Table 1. Nasal Symmetry Comparisons

<table>
<thead>
<tr>
<th>Measurement</th>
<th>Surgery Alone Group (%)</th>
<th>Surgery with NAM Group (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nasal tip projection</td>
<td>75.3 ± 1.7</td>
<td>76.5 ± 2.3</td>
</tr>
<tr>
<td>Nasal base height*</td>
<td>76.4 ± 2.7</td>
<td>76.4 ± 2.9</td>
</tr>
<tr>
<td>Columella deviation*</td>
<td>98.6 ± 2.7</td>
<td>98.1 ± 3.2</td>
</tr>
<tr>
<td>Supraorbital arc groove*</td>
<td>91.4 ± 6.3</td>
<td>90.9 ± 6.9</td>
</tr>
<tr>
<td>Medial crani nasal bone</td>
<td>92.5 ± 6.8</td>
<td>91.1 ± 6.1</td>
</tr>
<tr>
<td>Nasal bridge deviation*</td>
<td>92.1 ± 2.4</td>
<td>97.7 ± 1.7</td>
</tr>
</tbody>
</table>

*NAM: Nasal Airflow Monitoring

Statistical significance: p < 0.05
Comparative Study of Nasoalveolar Molding Methods: Nasal Elevator Plus DynaCleft® Versus NAM-Grayson in Patients With Complete Unilateral Cleft Lip and Palate

Luis Monasterio, M.D., Alison Ford, M.D., Carolina Gutiérrez, D.D.S., Maria Eugenia Tasates, R.N., Jacqueline Garcia, R.N.

Cleft Palate-Craniofacial Journal, September 2013, Vol. 50 No. 5

<table>
<thead>
<tr>
<th>Variable</th>
<th>Initial</th>
<th>Post</th>
<th>Total Difference</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleft width, mm</td>
<td>-0.299</td>
<td>-1.041</td>
<td>-0.742</td>
<td>.269</td>
</tr>
<tr>
<td>Cleft length, mm</td>
<td>0.64</td>
<td>0.513</td>
<td>0.127</td>
<td>.313</td>
</tr>
<tr>
<td>Columellar angle, degrees</td>
<td>-1.070</td>
<td>-0.697</td>
<td>-0.373</td>
<td>.333</td>
</tr>
</tbody>
</table>

* P > .05.

Unilateral Cleft Lip
Unilateral Cleft Lip

![Image of a baby with a unilateral cleft lip]

Unilateral Cleft Lip

![Image of a baby with a unilateral cleft lip]
Unilateral Cleft Lip

Unilateral Cleft Lip
Bilateral Cleft Lip

Bilateral Cleft Lip
Bilateral Cleft Lip

39

Bilateral Cleft Lip

40
Bilateral Cleft Lip

Impact on Postnatal Care

Prenatal Counseling’s Effect on Rates of Neonatal Intensive Care Admission for Feeding Problems Cleft Lip/Palate Infants

Abstract

Prenatal counseling and feeding instruction is standard at our institution for parents of cleft lip and palate patients. We studied this intervention’s effect on Neonatal Intensive Care Unit (NICU) admission solely for feeding. Ten percent (2/20) of patients whose parents received counseling were admitted to the NICU for feeding issues alone compared to 21% (5/24) of the non-counseling group. Prenatal counseling and feeding instruction appears to decrease NICU admission, duration and health care costs.

Table 1

<table>
<thead>
<tr>
<th>Admission for Comorbidity</th>
<th>Admission for Feeding</th>
<th>No Admission</th>
<th>P-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling</td>
<td>3</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>No Counseling</td>
<td>6</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

P-value* = 0.01

Table 2

<table>
<thead>
<tr>
<th>Admission for Comorbidity</th>
<th>Admission for Feeding</th>
<th>No Admission</th>
<th>P-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>No Counseling</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

P-value* = 0.18
Impact on Postnatal Care

Postpartum Depression in Mothers of Infants With Cleft Lip and/or Palate

Alexis E. Johns, PhD, ARPP; Jennifer A. Hardyfield, PhD; Netamet Malungo Setzla, RN, MSN; and Karla A. Haynes, RN, MPH

Abstract: This study describes postpartum depression rates and risk factors for mothers with infants with cleft lip and/or palate as postpartum depression has been associated with a range of negative maternal and child outcomes. A retrospective chart review from August 2009 to May 2015 included medical diagnoses, demographics, receipt of prenatal diagnosis, and the Edinburgh Postnatal Depression Scale (EPDS). Mothers (N = 206) had infants (59.2% male; mean age in weeks 5.1 ± 6.9) with isolated cleft lip (18%), cleft palate (22.8%), or cleft lip and palate (59.2%). Mothers ranged from 16 to 45 years old (mean age 29 ± 6.2) and half had received a prenatal diagnosis. Patients mostly had public insurance (57.8%) and represented diverse ethnicities. Based on the EPDS, 11.7% of mothers met the depression cutoff of 10 or higher. The majority endorsed self-blame (66.9%), difficulty coping (59.2%), and feeling anxious (57.3%). Mothers of infants with cleft lip or cleft lip and palate who did not receive a prenatal diagnosis had higher total EPDS scores, anxiety, and incidence of feeling scared. Higher EPDS scores were predicted by not having a prenatal diagnosis and by older maternal age. Mothers of infants with a cleft had similar rates of postpartum depression as the general population; however, those who were older and who did not receive a prenatal diagnosis endorsed more symptoms. Prenatal diagnosis may contribute to positive maternal postpartum adjustment. Providers should incorporate screening for risk factors into their evaluation and treatment planning.

Impact on Postnatal Care

The impact of having a baby with cleft lip and palate on parents and on parent-baby relationship: the first French prospective multicentre study

Iiro Grellemand, Lucile Despax, Pascale Guevreis, Carla Perez Martinez, Jimmy Muller, Toni Aflakou, and the CLEP Team (Cleft Lip & Palate Infants Parent)

Abstract: Background: The objective of this prospective, multidisciplinary and multicentre study was to explore the effect of a cleft lip, associated or not with a cleft palate, on parents, on parent-infant relationship and on the baby's relational development. It also highlighted how the type of cleft and the timing of the surgery could impact this effect.

Method: 158 infants, with Cleft lip with or without Palate, and their parents participated in this multicentre prospective cohort. Clinical evaluations were performed at 4 and 12 months postpartum. The impact on the parents and on the parent-infant relationship was evaluated by the Parenting Stress Index (PSI), the Edinburgh Post-partum Depression Scale (EPDS) and the Impact of Family Scale (IFS). The relational development of the infant was assessed using the Alienation and Stress Baby Scale (AABS). The main criteria used to compare the infants were the severity of cleft and the time of surgery.

Results: The timing of surgery, the type of malformation or the care structure had no effect on social withdrawal behaviors of the child at 4 and 12 months postpartum (AABS). Furthermore, early intervention significantly decreased maternal stress assessed with the PSI at 4 months. Parents for whom it had been possible to give a prenatal diagnosis were much better prepared to accept the waiting time between birth and the first surgical intervention (IFS). Higher postpartum depression scores (EPDS) were found for both parents compared to the general population.

Conclusion: A joint assessment of the mental health of both infants and parents is required in the follow-up of cleft lip and palate. Even if most families are remarkably resilient faced with the major cause of stress, a significant proportion of them could require help to deal with the situation, especially during the first year of follow-up. An assessment of the child's social withdrawal behaviour and of the parental stress and depression appears useful, in order to adapt care to infant and parent's needs.
Building Cleft Support System

American Cleft Palate–Craniofacial Association

myFace
Changing Faces, Transforming Lives

Buildings

Building Cleft Support System

![Image of a man and a child]
Building Cleft Support System
Building Cleft Support System

Building Cleft Support System
Building Cleft Support System

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Landon Stack
A Family Journey

• Our story
• The tough questions and issues
• Finding the team
• Going on the journey

Question & Answer
Closing Remarks

Stephanie Paul
Executive Director
myFace

For additional information and resources visit myFace.org

Or email us at info@myface.org
Thank You