

ORAL HEALTH IN COMPREHENSIVE CLEFT CARE



Content developed by the Oral Health in Comprehensive Cleft Care Task Team:
P. Mossey, Muthu MS, H. Zhu, M. Campodonico, L. Orenuga
Managing editors: P.Sheeran and R. England

This educational resource was produced as part of a partnership between FDI World Dental Federation and Smile Train, with support from GlaxoSmithKline Consumer Healthcare (GSK CH). No editorial control, apart from ensuring compliance with legal and regulatory considerations/requirements, has been exercised by GSK CH. Funding for the development of this educational resource was provided by GSK CH.



Contents

Executive summary	4
Chapter 1	5
Introduction	5
Why oral health is an essential element of comprehensive cleft care	6
What are orofacial clefts?	7
Aetiology of orofacial clefts	8
Genetics of orofacial clefts	9
Environmental risks and orofacial clefts	9
Maternal nutrition and orofacial clefts	10
Demographic factors of orofacial clefts	10
Clinical significance and implications of orofacial clefts	10
Oral health and dental problems	11
Chapter 2	13
A policy framework for cleft prevention and care	13
Raising awareness of cleft primary prevention	13
Ensuring access to timely surgery for people born with orofacial clefts	14
Promoting oral health and oral disease prevention for people with orofacial clefts	15
Patient education, health coaching, and brief oral hygiene interventions	16
Early detection: 'Lift the Lip' and oral disease risk assessments	16
Interprofessional education and collaboration	18
Translating advocacy objectives into action	18
Getting your facts right	19
Identifying and analysing government policies and commitments	20
Formulating goals and objectives	21
Identifying target audiences	22
Forming partnerships	22
Choosing the right advocacy activities and materials	23
Chapter 3	24
Key messages	24
References	26

Oral Health in Comprehensive Cleft Care

Executive Summary

Orofacial clefts are the most common craniofacial congenital anomaly worldwide and the second most frequent congenital anomaly, representing on average one in every 700 live births globally.¹⁻⁴ About 200,000 babies are born with cleft lip and/or palate every year.² These individuals are at increased risk of developing dental caries, periodontal (gum) diseases, and other maxillofacial, dental and well-being issues across their life course, making oral healthcare an essential component of their patient journey.

Early intervention and interdisciplinary care are required to ensure that these individuals lead long, healthy and fulfilling lives.

This Advocacy Guide is designed to provide guidance for national dental associations, policymakers, and health professionals. It suggests how to implement evidence-based policies that integrate oral healthcare into cleft care as part of comprehensive noncommunicable disease (NCD) programmes, as well as Universal Health Coverage (UHC) benefit packages.

Integrated care practices require policies that enable and support collaboration between health professionals and allow the exchange of dental and medical records, to support informed decision-making and people-centred care. This collaborative approach needs to be anchored in the education of health professionals, who should receive continuing training on the needs, forms and evidence for integrated care.

In May 2021, the World Health Assembly approved at its 74th session a World Health Organization (WHO) resolution on oral health (resolution WHA74.5), considered to be a “landmark” by WHO’s Director-General, Dr Tedros Adhanom Ghebreyesus. This resolution is indeed a milestone - it puts oral health back on the global health agenda; however, orofacial clefts were not mentioned as part of the global burden of oral diseases.

FDI World Dental Federation (FDI) and Smile Train have advocated for the inclusion of orofacial clefts in WHO’s follow-up Global Strategy for tackling oral diseases (to be approved by the World Health Assembly in 2022). Encouragingly, the initial draft of the Global Strategy⁵ includes orofacial clefts within the oral health response, mentioning also the shared risk factors of orofacial clefts with other NCDs.

Advocacy is an evidence-based approach to policy change. This Advocacy Guide presents a range of goals and objectives which represent the ultimate aim of the FDI and Smile Train partnership, namely to reduce the burden of caries by shifting the focus from a restorative to a preventive approach.

Depending on local settings, resources, and priorities, your advocacy campaign might focus on one or several objectives. Objectives must be translated into a set of actions, such as convening a meeting, seeking an appointment with local authorities or high-level officials, starting a mass media campaign or staging a public event. To support these actions, different types of advocacy materials can be prepared, such as fact sheets, leaflets, press releases, blog posts, tweets, etc.

FDI sets out in Chapter 3 five key messages on orofacial clefts to help advocates frame high-level discussions with national policymakers.

CHAPTER 1

Introduction

From the moment they are born, individuals with orofacial clefts, or cleft lip and/or palate (CLP), face many challenges. Orofacial cleft treatment requires a continuum of care, which may include surgery, orthodontics, oral healthcare, nutritional support, speech therapy and psychosocial support. This often involves craniofacial surgeons, paediatricians, orthodontists, paediatric dentists, dental hygienists, dental therapists and other oral health professionals, otolaryngologists, speech and language specialists, audiologists, genetic counsellors, nurses and social workers, constituting an interdisciplinary cleft care team.

Unfortunately, many of the 200,000 babies born with cleft each year lack access to some or all of these critical components of care. As a result, they struggle to feed, thrive or even survive.

The long-term surgical outcome and overall health of an individual with cleft will depend upon a foundation of good oral health. Due to a combination of genetic and environmental factors, individuals with cleft are more prone to oral health challenges, including dental caries, dental malformations and tooth malposition or malocclusion.

Without preventive and ongoing care, these oral health issues can cause additional pain, stress, anxiety, and serious health problems. They can prevent a child from attending school and an adult from finding secure employment. They can impact a child's friendships and an adult's role within their community. Thus, oral health complications can impact their quality of life at all ages.

For individuals with cleft, access to oral healthcare can make all the difference. Therefore, it is essential that all members of the cleft care team—including the individuals' families and the individuals themselves - have the knowledge and resources they need to prevent oral health issues and support good oral health at every stage of care.

Smile Train, the world's largest cleft lip and palate non-profit organization, empowers local medical professionals to treat people with cleft in their communities, supporting high-quality, comprehensive cleft care and strengthening health systems overall. This sustainable approach allows Smile Train to focus not only on supporting treatment while reducing and eliminating inequities in health but also promoting health and preventing disease. Oral health education in cleft care is vital to support disease prevention.



In 2019, Smile Train and FDI, with critical support from GlaxoSmithKline Consumer Healthcare, came together in a multi-year partnership to create guidelines and educational resources for optimal oral healthcare for infants, children and adults with orofacial cleft. This partnership enables providers to ensure individuals with cleft can improve their oral health outcomes via prevention and access to oral health services.

As one of the world's most common congenital anomalies, orofacial clefts contribute significantly to the global burden of disease. Addressing orofacial clefts through oral health interventions is therefore a powerful strategy for oral disease prevention in an often marginalized population group. Importantly, this approach also contributes to advancing health for all as part of the Universal Health Coverage (UHC) and the Sustainable Development Goals (SDGs) agendas.

“ I am grateful to have participated in dialogues around NCDs and represent individuals who are born with a cleft. Growing up, I did not have the opportunity to receive the surgery and care I needed and this became a challenge for me and my family. It not only affected my physical well-being, but also my psychosocial health. Now that I have received the care I needed, I hope to be able to speak out for those who are not as fortunate in my own little way. I try my best to speak and represent the cleft community as best I can and have offered to support others individuals who may need some guidance and encouragement. I hope that through these platforms, we can raise awareness about these challenges and contribute to policies and actions that truly give others an opportunity to receive timely care and enable them to live happier, healthier, and more productive lives.

Cris Daryl Magallanes, the Philippines
Patient and Cleft Lip and Palate Advocate
Real Estate Professional

Why oral health is an essential element of comprehensive cleft care

Orofacial clefts are a significant public health problem affecting 1 in every 700 births worldwide.^{6,7} An orofacial cleft affects the structures of the face and mouth and has an impact on critical functions such as speech, chewing, swallowing, breathing and facial expression, among other daily actions.

Oral health has been defined as multi-faceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow, and convey a range of emotions through facial expressions with confidence and without pain, discomfort, and disease of the craniofacial complex.⁸ According to this definition, orofacial clefts challenge the health and well-being of individuals in many ways, making oral health an indisputable requirement for inclusion in comprehensive cleft care.

Good oral health is a basic human right, but one that is enjoyed by all too few. Although oral diseases are largely preventable, the global burden of oral disease remains unacceptably high, tooth decay (dental caries) being the most prevalent condition globally.⁹ This applies to global populations - individuals with cleft tend to have a higher risk and prevalence of dental caries in both permanent and primary teeth.¹⁰

While rehabilitation and care of individuals living with cleft involve the core specialities of nursing, plastic surgery, speech therapy and orthodontics, good quality oral healthcare is also essential to ensure successful long-term health outcomes.^{11,12}

Dental care begins immediately after birth and extends into adulthood.¹³ The dentist should be present at almost all stages of comprehensive cleft care and work collaboratively with surgeons, ear-nose-throat (ENT) specialists, speech therapists, hearing specialists, nurses, psychologists, and the caregivers, families, and the individuals themselves.¹⁴ (Image 1)

“ The ideal team interaction results in team members who not only learn about the other involved disciplines but who can communicate comfortably in common terms allowing for a unified frame of reference concerning the patient”.¹⁵

Prof. Peter Mossey.

Oral Health in Comprehensive Cleft Care Task Team Chair

Professor of Craniofacial Development, Associate Dean for Internationalisation

Dundee University Dental School, United Kingdom

In joint decision-making, there should be a sharing of status and knowledge with team members and a willingness to learn about other disciplines.

Specific factors around cleft, such as a surgical scars, hypoplastic defects, misaligned teeth or a general predisposition to carious lesions, may influence the development of early childhood caries in young children with cleft.^{15,16} Furthermore, poor oral health will, directly or indirectly, affect different stages of the treatment. For instance, missing teeth due to dental decay or misalignments of the dental arches will have an impact on speech therapy, while periodontal disease or oral infections are factors for higher risk of infection after a surgical procedure like a bone graft. Consequently, there is a need for careful pre-operative planning and good oral hygiene to ensure successful outcomes in comprehensive cleft care.¹²

Oral Health Professionals

Cleft Oral Health Guidelines (by age group in years)

Routine Care

It is essential to achieve minimally invasive dentistry and maintain primary dentition

Restorative Tips

Orthopedic and Orthodontic Tips

	0-2	2-6	6-12	12-18	18+
Professional Advice	<ul style="list-style-type: none"> Explain to patients and their parents or guardians the causes of tooth decay & gum disease Professional fluoride application Scar management should be explained to caregivers and patients 				
Routine Care	<ul style="list-style-type: none"> Age appropriate oral hygiene - toothbrushing, mouth cleansing Dietary advice - nighttime feedings, baby bottles Fluoridated toothpaste use, fluoride supplements if required 		<ul style="list-style-type: none"> Age appropriate oral hygiene - toothbrushing, interdental cleaning, and tongue cleansing Dietary advice - avoid fizzy drinks, cariogenic snacks Fluoridated toothpaste use Periodontal examination Radiographic monitoring 		
	<ul style="list-style-type: none"> Obturator/appliance cleansing 	<ul style="list-style-type: none"> Discuss adverse habits - thumb sucking/pacifiers/clinching, bruxing and nail biting - and injury prevention 		<ul style="list-style-type: none"> Discuss adverse habits - bruxing, nail biting, and smoking - and injury prevention 	
			<ul style="list-style-type: none"> Fissure sealants as molars/premolars erupt 		
	<ul style="list-style-type: none"> Identification and monitoring of white/brown spot lesions 				
Restorative Tips	<ul style="list-style-type: none"> Silver diamine fluoride (if available) Atraumatic Restorative Treatment (ART) using adhesive materials such as glass-ionomer Stainless steel or zirconia crowns Direct bonding 				
			<ul style="list-style-type: none"> Partial dentures for missing teeth should be reviewed regularly for growing 	<ul style="list-style-type: none"> Partial dentures for missing teeth Begin considering cosmetic requirements - resin bonded-bridges, crowns, veneers 	
				<ul style="list-style-type: none"> Tooth whitening if required 	
Orthopedic and Orthodontic Tips	<ul style="list-style-type: none"> Referral to dental team if necessary Brief oral hygiene intervention (page 17) Presurgical infant orthopedics (PSIO) or palatal obturators 	<ul style="list-style-type: none"> Interceptive orthodontics if required Consider space maintainers if any primary teeth are lost 	<ul style="list-style-type: none"> Interceptive orthodontics/orthopedics Assess need for alveolar bone graft (ABG), maxillary and/or palatal expanders Maxillary orthopedic protraction if required 	<ul style="list-style-type: none"> Assess the need for jaw surgery and specific orthodontics to correct severe malocclusion 	
	<ul style="list-style-type: none"> Care of the PSIO or obturator (page 17) 				
	<ul style="list-style-type: none"> Care of orthodontic appliances 				

IMAGE 1: ORAL HEALTH IN COMPREHENSIVE CLEFT CARE GUIDELINES FOR ORAL HEALTH PROFESSIONALS

Governments should incentivize the creation of cleft care teams. The role of a cleft care team is to help sustain oral health proactively during all the treatment stages, making multidisciplinary care people-centred, comprehensive, and effective. Good oral health will reduce discomfort in individuals with cleft and reduce the expenditure of individuals, their families, and the organizations that sustain comprehensive cleft care.

What are orofacial clefts?

Orofacial clefts are a heterogeneous group of congenital anomalies affecting the structure of the face and oral cavity when parts of the lip and/or palate and nose do not fuse together during embryonic development.

Orofacial clefts can be divided into three general categories with variability in phenotype:

1. unilateral or bilateral cleft lip with or without cleft alveolus;
2. unilateral or bilateral cleft lip and palate;
3. cleft palate alone.

A classification system that can comprehensively cover all orofacial cleft variations and sub-phenotypes and be standardized is essential. This would allow consistent recording, registration and comparisons between centres, regions, and populations for clinical governance and research purposes. The LAHSAL system¹⁷ is an example of such a classification system and could be standardized internationally.

Aetiology of orofacial clefts

Orofacial clefts are the single most commonly treated craniofacial anomalies in a paediatric hospital setting. They represent an important burden for health systems, and significantly impact health economics due to the medical cost of surgery and treatment. They have a considerable impact on the social life and personal well-being of individuals with cleft and their families, with a resultant effect on their oral health-related quality of life. Other consequent effects are due to the number of associated complications, which often require long-term medical attention, including:

- feeding difficulties;
- speech and language delays;
- ear infections and possible hearing loss;
- aesthetic challenges;
- oral health concerns, e.g. dental caries, periodontal diseases, malocclusion;
- reduced quality of life;
- psychological, psychosocial (stigma) and economic implications.

Orofacial clefts occur when there is a derangement in the embryonic development between the 4th and 12th week of pregnancy when many women may be unaware of their pregnancy. Orofacial clefts are a complex multifactorial disease in which both genetic and environmental factors play a role.^{3,4,18}

The risk factors identified with increased incidence of orofacial clefts include vitamin deficiency, especially folic acid deficiency, B6, B12, and zinc; maternal tobacco, alcohol or drug use; and chemical exposure during pregnancy.^{12,14,18}

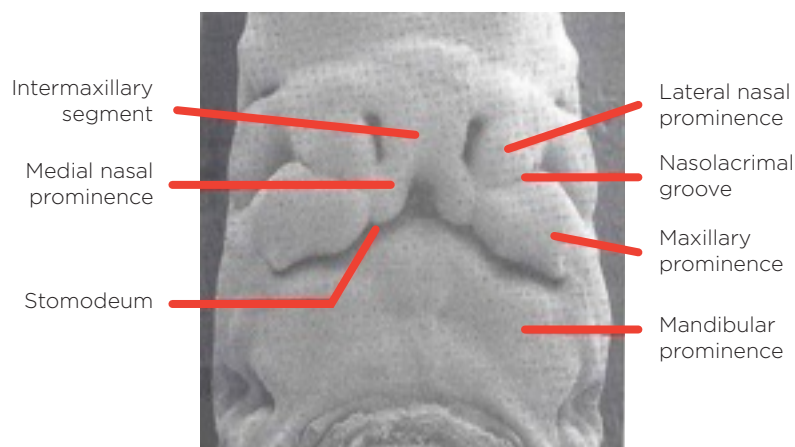


IMAGE 2: EMBRYO AT 4-7 WEEKS OF INTRA-UTERINE LIFE

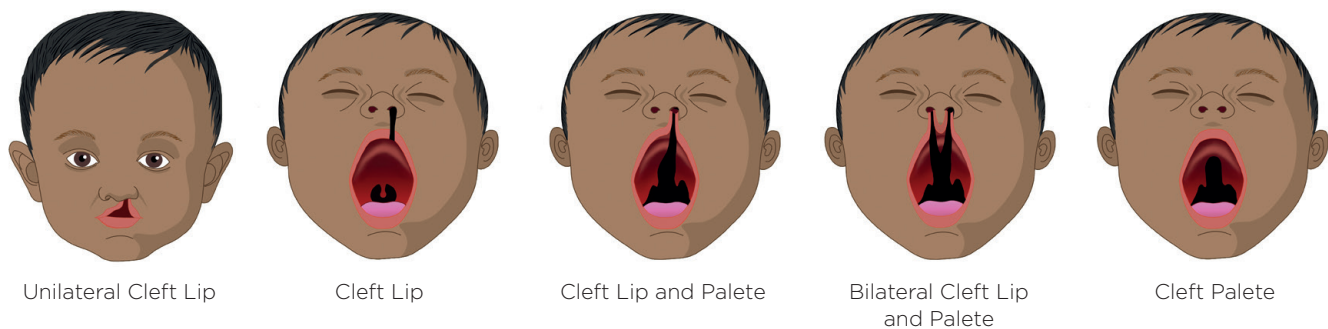


IMAGE 3: OROFACIAL CLEFT AFFECTING THE HARD PALATE

Genetics of orofacial clefts

Orofacial clefts can be classified as syndromic or non-syndromic. Syndromic clefts are caused by specific genetic conditions and with a recognized pattern of human malformation or syndrome. The cause of a syndromic cleft may be associated with gene transmission, chromosomal anomalies, teratogens or environmental factors. However, since the advent of genomic medicine, there have been major advances in identifying the causative genetic mutations of underlying syndromic forms of orofacial clefts.^{3,20-22}

There are more than 600 types of syndromic orofacial clefts and not all of them are hereditary. Van der Woude syndrome (VDWS) is the most common heritable form of syndromic orofacial cleft, and individuals living with this syndrome account for 2% of all cleft cases. Other syndromes associated with orofacial clefts include velocardiofacial syndrome (VCFS), orofaciодigital syndrome type 1 (OFD1), Robin sequence, and Stickler syndrome.

Non-syndromic orofacial cleft aetiology is considered to be multifactorial and determined by interactions between many loci genes and environment, based on epidemiological and experimental data.^{20,21} In addition, many candidate genes have been, and still are being, investigated to elucidate the underlying genetic mechanism causing orofacial clefts.

The genetic risk for having a child born with an orofacial cleft for a couple in which one of them has a cleft or already have a child with a cleft is approximately 4%, with variation according to factors such as cleft type and severity, number of affected siblings or relatives, sex of the siblings, and presence of other features or conditions.

Environmental risks and orofacial clefts

Because orofacial clefts are formed during embryogenesis, the fetal environment is crucial; the aetiology of orofacial clefts are affected by the family's genes as well as the mother's lifestyle and environmental exposure. The concept of environmental risks is complex and broad, and orofacial clefts have frequently been associated with infections, pollutants, radiation exposure, risky behaviours and diet.

As mentioned, non-syndromic orofacial clefts represent a heterogeneous range of polygenic multifactorial disorders caused by the interaction of multiple genes and also environmental risk factors. While there is substantial evidence that genetic factors contribute to orofacial clefts, the complex mode of inheritance involving both genetic and environmental influences is less understood.

Recently, the US Centers for Disease Control and Prevention has reported significant findings from research studies into the factors in pregnancy that increase the chance of having a child with an orofacial cleft, including smoking, alcohol, diabetes and the use of certain medications.^{1,23}

These include:

- Women who smoke during pregnancy are more likely to have a baby with an orofacial cleft than women who do not smoke;
- Women living with diabetes before pregnancy have an increased risk of having a child with an orofacial cleft than women who do not live with diabetes;
- Women who used certain medicines during the first trimester of pregnancy to treat epilepsy, such as topiramate or valproic acid, have an increased risk of having a baby with an orofacial cleft, compared to women who did not take these medicines.

Maternal nutrition and orofacial clefts

At the time of conception and during the first trimester of pregnancy, the mother's nutritional status is important in the development of orofacial clefts and other craniofacial structures of the fetus. During this critical stage of development, several key nutrients have been implicated in the development of orofacial clefts: folic acid, vitamin B12, vitamin B6, and zinc.

Maternal ability to maintain adequate levels of vitamins B6 and B12 and fetal ability to utilize these nutrients are also seen as factors in the development of orofacial clefts. When these nutrients are not appropriately metabolized, DNA synthesis and transcription errors may occur, leading to congenital anomalies.

Demographic factors of orofacial clefts

Orofacial clefts are the most common congenital anomalies of the face that can occur due to genetic and environmental factors, but variability across geographic origin, race, ethnic groups and socio-economic status may also influence their development.

Caucasians have an average incidence of 1 in 700 births; individuals of African descent have the lowest incidence of approximately 1 in 1,200 births. The gender distribution of orofacial clefts is unequal too. The incidence of orofacial cleft is twice as high in men compared to women, whereas that of cleft palate alone is higher in women.

Clinical significance and implications of orofacial clefts

Depending on the type and severity of the cleft, individuals with orofacial clefts face various health and social challenges both in the early years of life and in adulthood. In some settings, such as in large rural areas of Central America, India, Indonesia, and Sub-Saharan Africa, only a small percentage of infants born with orofacial clefts survive the first few weeks of life.²⁴

Difficulty in feeding

One of the most immediate concerns after the birth of a child with cleft is feeding. While most babies with cleft lip can breastfeed, a cleft palate may make sucking difficult, leading to complications around nutrition and growth.

Ear infections and hearing loss

Babies with cleft palate are at increased risk of developing middle ear fluid and hearing loss. In addition, they often experience persistent middle ear infections.

Speech difficulties

Because the palate is used in the formation of sound, a child with cleft palate can find the development of their speech is affected.



Psychosocial challenges

Individuals with cleft may face social, emotional, and behavioural problems due to differences in appearance, communication and the stress of intensive medical care. As children they may exhibit shy, nervous, or unco-operative behaviour.²⁵

Oral health and dental problems

Orofacial clefts affect multiple areas of the mouth, leading to diverse problems in the oral cavity, exacerbated by prolonged and ongoing surgical and orthodontic interventions. For instance, cleft lip often leads to aesthetic problems. Cleft alveolus may lead to dental problems associated with the need for surgical repair, including a deficiency of maxillary development potentially leading to Class III malocclusion and a buccal segment open bite. In addition, tooth buds in the cleft area may be affected, giving rise to eruption problems and dental malformations.

Malformations can include hypodontia, supernumerary teeth, defects in tooth size, shape and form, such as enamel hypoplasia or dilaceration of the crown or root. These dental malformations may predispose people with an orofacial cleft to multiple food traps. This, in addition to poor oral hygiene practices, predispose a child with an orofacial cleft to poor oral health, resulting in periodontal diseases and dental caries, as reported by several studies.^{26,27}

Children with orofacial clefts may be additionally susceptible to dental caries at an early age due to a variety of other factors critical to a healthy mouth. They may:

- have medical conditions that require the prescription of sweetened, cariogenic medications;
- consume a diet rich in sugars;
- have poor oral hygiene practice;
- have low fluoride exposure;
- be insufficiently motivated to perform regular preventive dental home care;
- be exposed to early bacterial infection (*Streptococcus mutans* and *Lactobacillus*);
- be at risk of poor teeth alignment and high prevalence of dental erosion;
- experience altered salivary gland function and poor oral clearance after eating and drinking due to the burden of oral diseases.

Consequently, it is important that comprehensive measures for oral health promotion and oral disease prevention are targeted towards young children with orofacial clefts and their families. This will reduce their burden of oral diseases and ultimately improve their overall health outcomes; such measures should also reduce the psychosocial and economic impact of oral diseases on both individuals and their caregivers.^{28,29}

“ As a pediatric dentist, my goal is good oral health for my patients. Sadly, over 60% of children born with a cleft under the age of 6 already have experiences with caries and or periodontal disease. To achieve good oral health for patients with clefts, oral health professionals have to work in a team that includes not only the patient, their family and caregivers, but also the non-dental health professionals of the comprehensive cleft care team. Education in preventing oral health diseases will give the whole team the tools to speak the same language, give the same oral health guidance during appointments and reinforce these messages over time, inviting patients and caregivers to participate in their own oral health care. This will be the best way to achieve our goal; healthy, happy, smiling children and adults.

Dr Marina Campodonico

Pediatric Dentist & Presurgical Orthopedic, Fundación Gantz, Chile
Smile Train South America Medical Advisory Council



CHAPTER 2

A policy framework for cleft prevention and care

The health outcomes and economic dimension of both preventing and treating orofacial clefts are essential considerations. A study by Galloway et al. (2017) compared the average total cost of cleft treatment in high income countries, such as European countries, with low-income countries, such as India. When surgery, speech and language therapy, orthodontics, and orthognathic surgery are provided, the average total direct cost of cleft treatment is \$10,000-\$13,000 in the former, where the state health insurance often covers most costs, and \$3,000-5,000 in the latter, where patient and charity organizations fund most costs.

As they grow and develop, regardless of whether they undergo surgery, individuals born with orofacial clefts are at increased risk of oral disease; they require frequent oral health interventions to prevent oral diseases and to ensure their highest attainable standard of health. Studies have shown that for every \$1 spent on oral disease prevention, up to \$50 can be saved on treatment later in life.³⁰

The wide range of factors potentially linked to the development of orofacial clefts and the oral healthcare needs of individuals born with cleft, makes it imperative that a policy framework for cleft prevention and care is developed. The policy framework should aim to:

- raise the profile of orofacial clefts and their oral health implications as a public health concern and therefore a policy priority among decision makers; this should ensure that surgery and other health needs of individuals born with cleft are met without causing catastrophic health expenditure for households;³¹
- educate decision makers about the risk factors involved in the development of orofacial clefts and the role that primary prevention can have in reducing the prevalence of orofacial clefts and the risk of developing dental caries and periodontal diseases;
- address the social determinants of health so individuals born with cleft have equality of access to prevention and care and timely surgery when needed, decreasing their risk of developing oral diseases;
- ensure children born with cleft, and their caregivers, receive individual counselling and education to increase oral health literacy and understanding around the oral health implications of cleft;
- invest in interprofessional education for health professionals and multidisciplinary cleft care teams to increase their knowledge of oral health disease prevention and early detection, facilitating collaboration;
- digitalize medical and dental records within a compatible system to enable the exchange of information between multidisciplinary teams;
- promote information-sharing by patients, families, and communities to increase public awareness of orofacial clefts and their oral health implications.

Raising awareness of cleft primary prevention

Orofacial clefts are major, severe congenital anomalies recognized by the World Health Organization's (WHO) birth defects surveillance manual for programme managers (updated in 2020). In many rural and poor settings, only a small percentage of infants born with cleft survive the first weeks of life, especially when there is no access to safe and timely surgery. Also, low prevalence rates of orofacial clefts in certain regions could be due to the high rates of infant mortality and lack of surveillance capacity.³² Given the severity of orofacial clefts, as well as their economic impact, primary prevention is the ultimate objective for managing orofacial clefts.

A complex interplay of genetic and environmental factors influence the risk of developing orofacial clefts. Common environmental factors associated with a greater risk of developing orofacial clefts

include maternal risk factors such as exposure to tobacco, alcohol, certain chemicals, and medication; other factors might include poor nutrition, such as folic acid deficiency, obesity or infections during pregnancy.^{33,34}

While more research is required to understand the complex factors that influence orofacial clefts, it is essential that a focus on these risk factors is included in comprehensive strategies to reduce the global burden of orofacial clefts. It is also crucial to focus on secondary and tertiary prevention strategies, especially when it comes to ensuring good oral health and well-being for individuals born with cleft.

“As has been rightly said, “The mouth is a gateway to general health and a mirror for well-being.” Oral health is an integral part of general health, and this is especially true for patients with clefts, who often struggle with increased oral health challenges. Sustaining excellent oral health care is possible. Earnest efforts in this direction should begin as soon as the first tooth erupts in the oral cavity. The key to this is ensuring awareness and knowledge of oral health within the entire multidisciplinary cleft lip and palate team.

Dr M S Muthu

Head - Centre for Early Childhood Caries Research, Sri Ramachandra Institute of Higher Education and Research, India

Advocacy objectives around cleft primary prevention may include:

- recognize orofacial clefts as severe congenital anomalies, leading to high rates of infant mortality in rural and poor settings when there is no timely access to high quality surgery, and therefore the need to also focus on cleft primary prevention;
- ensure countries include primary prevention interventions in antenatal care to raise awareness about cleft risk factors and increase oral health literacy among pregnant women, to reduce family risk factors;
- facilitate access to secondary and tertiary prevention interventions for people born with cleft to maximize their quality of life and reduce their risk of developing oral health issues in the long-term.

Ensuring access to timely surgery for people born with orofacial clefts

In the absence of access to timely and safe surgery, the infant mortality rate of infants born with cleft is extremely high. 75% of children born with cleft will die by the age of 10 if they don't receive surgery. With surgery, 98.5% of these children survive.³²

Moreover, surgical care is cost effective. In an analysis of more than 500,000 cleft lip and palate treatment records collected over a ten-year period, disability-adjusted life years (DALYs) ranged between 1.46 and 4.95 million, and the mean economic impact ranged between \$5,510 and \$50,634 per person. This corresponded to a global economic impact of between \$3.0 billion and \$27.7 billion, depending on the DALY and gross national income values used, while the estimated cost of providing these procedures based on an average reimbursement rate was \$197 million (0.7-6.6 % of the estimated impact).³⁵

Advocacy objectives to improve access to timely and safe cleft surgery may include:

- raising awareness of the importance of timely access to high quality surgical care for infants born with cleft to reduce the mortality rate, preventing long-term oral health issues, and maximizing individuals' future health outcomes and well-being;³⁶
- promoting research in order to make the case on the cost-effectiveness of surgical care for people born with cleft, and showcasing examples of successful interventions to increase access to surgery for people born with cleft.

Promoting oral health and oral disease prevention for people with orofacial clefts

Individuals born with cleft are more susceptible to developing oral health and dental problems; it is therefore crucial to promote oral disease prevention from an early age among individuals and caregivers, oral health professionals, and the wider cleft care team. Table 1 illustrates some preventive strategies that each active member of the cleft care team, including individuals and caregivers, can adopt to prevent oral diseases and promote oral health in individuals born with cleft.

Individuals and caregivers	<ul style="list-style-type: none">• Ensure optimal oral hygiene;• Use fluoride-containing products;• Favour a healthy diet;• Seek regular dental check-ups;• Perform the 'Lift the Lip' technique for monthly monitoring.
Oral health professionals	<ul style="list-style-type: none">• Provide patient education on oral hygiene; practices and counselling on healthy diets;• Apply topical fluoride and pit-and-fissure sealants where appropriate for prevention of dental caries;• Perform regular examinations (periodontal and radiographic);• Provide treatment for progressing carious lesions including through atraumatic restorative technique and other minimally invasive interventions;• Advise on injury prevention.
Non-oral health professionals	<ul style="list-style-type: none">• Provide patient education, i.e. through a brief oral hygiene intervention at each appointment;• Perform the 'Lift the Lip' technique at each appointment, and make an oral disease risk assessment.

TABLE 1: ORAL DISEASE PREVENTIVE STRATEGIES FOR COMPREHENSIVE CLEFT CARE

As oral diseases are largely preventable and can start developing from an early age, the sooner these interventions begin, the more likely it is that they will be effective. Children born with cleft should already visit an oral health professional before their first tooth erupts and must have had their first check-up at the latest by the time of their first birthday. They should maintain regular monitoring and seek access to preventive care by an oral health professional, even if they are undergoing treatment with other members of the cleft care team. Early interventions can significantly decrease the risk of developing dental caries in mixed and permanent dentition, improving their quality of life in the long term, and allowing them to focus on other treatments and needs.

Patient education, health coaching, and brief oral hygiene interventions

Individuals born with cleft should be supported by oral and non-oral health professionals to acquire an optimal level of oral health literacy. Health professionals may rely on patient education techniques such as health coaching or motivational interviewing to assist people in adopting good oral health behaviours. In this context, health coaching could involve agreeing on a few oral health goals in consultation with the individual so that they are empowered to make and monitor behavioural changes that will help prevent and/or alter the course of oral diseases.

Each contact with a health professional should be utilized to carry out a brief oral hygiene intervention. This proactive method, which is widely used in paediatric healthcare, is the process of providing practical, repeated rounds of oral health information to caregivers and/or individuals, leveraging as well the role of parents in ensuring their children maintain good oral hygiene practices.

Brief Intervention of Oral Hygiene for Non-Oral Health Professionals

Applies to all age groups

1 Brush twice per day for 2 minutes.

2 Use a fluoride toothpaste. (Spit, but don't rinse!)

3 Try not to snack between meals.

4 Snacks should be non-cariogenic—plain yoghurt, cheese, whole fruits.

5 Only water or milk should be given for drinks between meals.

6 Visit the dentist regularly.

IMAGE 4: A BRIEF INTERVENTION OF ORAL HYGIENE FOR NON-ORAL HEALTH PROFESSIONALS

Early detection: ‘Lift the Lip’ and oral disease risk assessments

Caregivers and members of the cleft care team should also engage in the monthly monitoring of the hard and soft oral tissues of children born with cleft by using the “Lift the Lip” technique, which allows identification of white or brown spots on enamel. In case an early carious lesion is identified, children should be referred as soon as possible to their oral health professional. This approach needs to be adopted by both caregivers and the wider cleft care community.

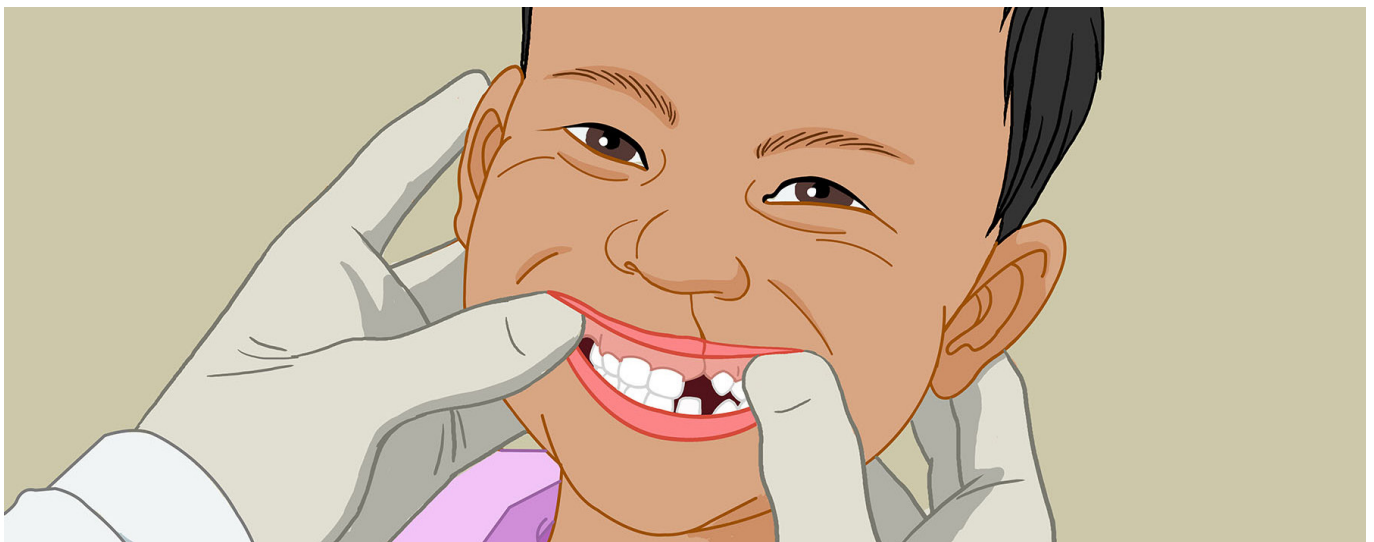


IMAGE 5: LIFT THE LIP



The cleft care team should also conduct a risk assessment to quickly understand if a child born with cleft is at higher risk of developing oral diseases. Each factor below - whether occurring on its own or in combination with other factors - increases each individual's risk of dental caries, periodontal diseases, and other oral diseases:

- active or previous carious lesions;
- low socio-economic status;
- frequent consumption of dietary sugars;
- reduced salivary flow or low salivary pH;
- poor oral hygiene;
- sub-optimal exposure to fluoride;
- family risk factors (use of indicators such as educational level of parents or sibling's oral health status).

Advocacy objectives around the need for oral health promotion and oral disease prevention for individual born with cleft may include:

- ensuring availability of oral healthcare services as part of national health scheme benefits, facilitating equitable access, financial protection and quality preventive and curative oral health services to individuals born with cleft;
- promoting the need to provide regular check-ups and early oral health preventive interventions by both oral health professionals and members of the wider cleft care team to individuals born with cleft;
- facilitating access by all members of the cleft care team to oral health educational materials, including for craniofacial surgeons, paediatricians, orthodontists, paediatric dentists, dental hygienists, dental therapists, speech and language specialists, otolaryngologists (ENT specialists), audiologists (hearing specialists), genetic counsellors, nurse team coordinators, social workers and psychologists.

Interprofessional education and collaboration

There is an urgent need to educate oral health professionals and the wider cleft care team. By promoting interprofessional education and collaboration, a comprehensive cleft care approach centered on the health and well-being of patients can be achieved. The provision of interprofessional education and the establishment of collaboration mechanisms for all care team members will ensure that oral health is part of the continuum of care for cleft.

Globally, improving oral health is a major population goal; however, providing preventive care for individuals born with cleft is often absent from the curricula in health sciences. Educational reform should encompass undergraduate, postgraduate, and continuing education.

Advocacy objectives around the need for interprofessional education and collaboration may include:

- improving the curricula of schools teaching health sciences to the care and medical community to ensure health professionals receive training on preventive oral healthcare for individuals born with cleft;
- ensuring basic oral healthcare training packages in health sciences institutions include background on the aetiology and prevention of clefts and oral diseases;
- increasing access to interprofessional education both in dental schools and at the healthcare level to promote a collaboration-ready workforce;
- facilitating access to continuing education activities for medical and oral health professionals to ensure up-to-date knowledge and best practice on the prevention, risks and treatment of individuals born with cleft.

Translating advocacy objectives into action

In May 2021, the World Health Assembly approved at its 74th session what WHO's Director-General, Dr Tedros Adhanom Ghebreyesus, has called a "landmark" resolution on Oral health.³⁷ This resolution stresses the worrying burden and human and economic cost of oral diseases while providing concrete follow-up actions for both members states and WHO to tackle poor oral health at country and global levels. It has a strong focus on prevention, multisectoral action, and integration into the UHC and Noncommunicable Disease (NCD) agendas.

The resolution does not include mention of orofacial clefts, but the updated WHO's Director-General Report on Oral Health does refer to the burden of orofacial clefts as the most common craniofacial congenital anomalies, leading to lifelong disability and often resulting in social exclusion for many. This development recognizes the need to address orofacial clefts as part of the oral health response. Moreover, FDI has also advocated the inclusion of oral health promotion and primary prevention and management of orofacial clefts as part of maternal, newborn and children health (MNCH) programmes in the context of WHO's Global Strategy for Women's, Children's and Adolescents' Health (2016–2030).

FDI concurrently released Vision 2030: Delivering Optimal Oral Health for All, which identifies challenges that will confront dentistry and the oral health community over the next decade. It calls for interprofessional collaboration to tackle the growing burden of oral diseases and common risk factors. The report further describes approaches to overcome these challenges to ensure the availability of equitable, affordable, and accessible oral health services for all.²⁴

There is an window of opportunity with the WHO resolution on Oral health and its follow-up actions, including the Global strategy on tackling oral diseases, an action plan for public oral health, and a menu of cost-effective interventions ("NCD Best Buys") for oral health management. For instance, the initial draft of WHO's Global Strategy on tackling oral diseases (to be approved by the World Health Assembly in 2022) encompasses orofacial clefts within the oral health response, mentioning also the shared risk factors of orofacial clefts with other NCDs.

International, regional, and local level policies have often not prioritized oral health within health systems strengthening efforts due to a lack of:

- political leadership, often associated with a lack of awareness from political leaders about the importance of oral health for general health and people born with cleft;
- prioritization within health and development agendas due to competing health and social issues;
- budget allocation dedicated to health promotion, oral healthcare, and NCD services more widely.

Advocacy is the process of building support for an issue through evidence-based arguments ensuring governments take on their responsibilities to protect the public interest. Implementing an advocacy strategy must be considered as a means for you to:

- Ensure that key decision makers know about existing policies and strategies, and are informed of their responsibility to implement them;
- Reinforce or foster the development of new policies to meet their responsibilities;
- Prioritize specific approaches, programmes, or services that will ensure their responsibilities and commitments are met;
- Help secure financial resources to implement these policies and strategies, delivering relevant programmes and services;
- Generate support among community members to create demand for the implementation of such policies and programmes.

In order to achieve results, an advocacy campaign must be carefully planned and prepared before implementation. It usually starts with background work (collecting the information and evidence, including main facts and figures, analyzing the situation, identifying your target audiences, etc.). Moreover, it requires elaborating clear goals and objectives for relevant activities and materials.

Getting your facts right

In order to meet your advocacy objectives, you need to ensure that you build a solid case, generate sufficient support, and reach the right people (i.e., influential support and even traditional opponents). The policymakers you will contact or meet are usually not oral health or orofacial cleft experts. They might be busy people who must oversee different priorities and requests. When addressing them, it is important to use plain and clear messages, avoiding technical terms. Bear in mind that when they are choosing actions and programmes to prioritise, the potential return on investment will always weigh heavily on their final decisions. Therefore, you need to make sure that you are able to bring convincing facts and evidence to support your argument, including on the cost-effectiveness of the programmes and services you are suggesting. Data-driven requests will help build your case and convince policymakers. Prior to convening a meeting, holding a press or a public event, it is advised to compile carefully any relevant data to support your arguments and requests.

Examples of useful data

Data related to disease status	<ul style="list-style-type: none">• data on the traditional decay-missing-filled teeth (DMFT) index or other data relating to the prevalence of dental caries in people born with cleft in your region, possibly compared with global data;• number of infants born with cleft annually in your country, region, or globally;• mortality rate of infants born with cleft in your country, region, or globally.
Data related to psychosocial function	<ul style="list-style-type: none">• oral health-related quality of life data among people born with cleft, such as satisfaction with physical appearance, feelings of shame in social interactions, etc;• data on missed work or school days by people born with cleft.
Data on health systems capacity	<ul style="list-style-type: none">• workforce statistics for people trained in basic oral healthcare available to people born with cleft;• number or scope of cleft lip and/or palate prevention programmes;• financing mechanisms for comprehensive cleft care and/or oral healthcare for people born with cleft;• cost-effectiveness analyses on paediatric surgery interventions for children born with cleft.



Identifying and analysing government policies and commitments

A review of existing government policies constitutes an essential step in understanding the government's position on the issue at hand. A range of diverse national policies, strategies, guidelines, parliamentary acts, laws and regulations might be available, which can potentially affect oral diseases in people with cleft and its prevention and management.

Table 2 outlines a few examples, which might differ depending on your country and setting.

Type of policy	Decision-making bodies
National health strategy or plan	Ministry of Health
National oral health strategy or plan	Ministry of Health
School oral health education programme	Ministry of Education
Reimbursement schemes for regular dental check-ups - or preventive care	Ministry of Health

TABLE 2: EXAMPLES OF EXISTING POLICIES

Formulating goals and objectives

Your advocacy campaign goals should be outlined in a broad statement that describes some general outcomes and objectives.

The objectives must be more specific and describe concrete results or outcomes to be achieved over a certain period of time. Setting "SMART" objectives is usually recommended, whereby:

- Specific - objectives are clearly defined, as are the actions needed to meet them;
- Measurable - results can be quantified and evaluated;
- Achievable - objectives must be possible to meet and likely to succeed;
- Realistic - resources and capabilities available are sufficient to achieve the desired outcomes;
- Time-bound - there is a clear time-frame for achieving the desired outcomes.

Examples of goals and objectives

Goal	Objective
Inclusion of essential oral healthcare services within the national health scheme's benefits	Advocate among local governments that oral healthcare is integrated into UHC within the next 5 years.
Ensure all individuals with cleft have access to oral disease prevention interventions by different health professionals	Train oral health and non-oral health professionals to make every contact count i.e. and carry out a brief intervention on oral health risks and oral hygiene for people born with cleft and their caregivers.

Identifying target audiences

An essential step in achieving advocacy goals and objectives is to determine the right target audiences.

These include individuals who are:

- Influential
- Supportive (or not)

In addition to identifying individuals or groups who can directly affect your desired outcomes, i.e. decision makers, you also need to identify individuals or groups who can influence your primary audience. Once you have identified your potential target audiences, you need to focus on those who are likely to be the most influential.

Do not forget that strong opponents are also an important target audience; adequate information and education might turn them into allies instead of opponents. Depending on your advocacy objectives, your primary target audience might be a Minister of Health, elected officials, local community leaders, a group of school principals, the wider public, etc.

Forming partnerships

Partnerships across a wide spectrum of organisations are essential to ensure adequate prevention, management and control of oral diseases in people with cleft. In the field of oral health promotion, they can be formed with stakeholders with differing levels of responsibility or influence:

- patients
- coalition of oral health professionals
- wider cleft care team
- health facilities
- non-governmental organizations
- government and policymakers
- product manufacturers
- taxpayers

Selection of the right partners strongly depends on the objectives that have been set. For example, suppose your aim is to convince your national government to implement oral health education at every patient contact. In that case, you might wish to seek an alliance with other health associations (diabetes, obesity, etc.), and with the public health community. Suppose your aim is to introduce oral health education programmes in healthcare settings. In that case, you might wish to collaborate with educators and perhaps with product manufacturers, as they might be able to provide materials such as toothbrushes and fluoride toothpaste.

Partnerships are vital because they allow you to reinforce your action. They can be long-term but also temporary. Bear in mind that there might be some overarching goals and objectives when multiple partners work together on an advocacy initiative. However, each partner might also set a few separate, complementary goals and objectives. This is not in itself an issue, but it should be clarified from the outset to ensure that individual objectives are not at odds with your own goals and objectives.

Choosing the right advocacy activities and materials

Once your target audiences are identified, their characteristics can be determined (position, age, level of education, access to media, social media, knowledge about the issue, etc.). These characteristics should help you select the most appropriate advocacy activities and materials. Based on the likely preferences of your target audiences, different types of advocacy activities can be set up.

- **Workshops and meetings:** setting up meetings and workshops with a target group of individuals (local officials, community leaders) to present and discuss the issue can be a powerful means of raising awareness and generating support for your advocacy objectives.
- **High-level meetings:** scheduling a meeting with a high-level official is a further means to drive forward your advocacy efforts. This will require thorough preparation as you will have limited time to present a convincing case. Direct support from a high-ranking elected official, such as a Minister of Health, can be instrumental in successfully achieving your advocacy goals and objectives.
- **Public events:** these can take different forms, such as an awareness-raising campaign in a busy public place, interactive games and quizzes, a toothbrushing contest etc. Such events can help engage the wider community in your advocacy efforts. They can be timed to coincide with important dates in the calendar, such as World Oral Health Day (www.worldoralhealthday.org) on March 20th and World Smile Day, celebrated on the October 2nd in many countries around the world. A public gathering to mark a significant event will engage a wider audience and should obtain good media coverage, which in turn helps raise awareness among local and national authorities.
- **Mass media campaign (newspapers, radio, TV):** the strength of mass media is in its potential to reach large audiences. It can help generate support from the community to build pressure on elected officials to take action. It is however, not very well suited to reach a well-defined, narrow group of individuals, such as decision makers.
- **Social media (websites, blogs, Facebook, Twitter):** social media increasingly represents a powerful channel to communicate advocacy goals and objectives. It can amplify your advocacy efforts by reaching more people in very little time. Social media has very low set-up costs and offers new opportunities to engage with your target audiences. Preparing and disseminating a set of messages (blog posts, Facebook posts, tweets) pertaining to your advocacy goals and objectives can represent powerful support to achieve your aims.
- **Printed materials:** materials such as booklets, leaflets or factsheets are valuable to support your advocacy activities. It is useful to distribute printed materials to document your advocacy goals and objectives when you organize a meeting or activity. However, disseminating printed materials to target audiences without any supporting activities is unlikely to be sufficient to achieve your aims.

“ Children with cleft lip and palate are more susceptible to a variety of dental and periodontal diseases as well as common dental anomalies like missing teeth and supernumerary teeth. Robust oral health education policy and resources for interdisciplinary cleft team members, as well as education around cleft lip and palate for oral health care professionals, would have the potential to reduce the amount of dental and orthodontic care needed to create an optimal outcome for patients while reducing the overall global burden of oral disease.

Dr. Puneet Batra, Professor and Director Postgraduate Board of Studies,
Manav Rachna Dental College, Faridabad, Haryana
Member, Dental Council of India Member,
Smile Train Advisory Council (India)
Consultant Cleft Orthodontist at Sant Parmanand Hospital (New Delhi)
and Global Hospital and Research Centre Mt Abu (Rajasthan).
Past President of the Indian Society of Cleft Lip and Palate & Craniofacial Anomalies

CHAPTER 3

Key messages

In this Advocacy Guide, FDI and Smile Train offer five key messages for national dental associations and other stakeholders to communicate in their high-level discussions with national decision makers.

1. Orofacial clefts are the most common congenital anomalies of the face and mouth and are a significant public health problem. They are a complex multifactorial disease in which both genetic and environmental factors play a role. The presence of orofacial clefts results in medical, psychological, and social problems in affected individuals and their families. Infants born with cleft have significant needs from multiple healthcare specializations, including the involvement of plastic/craniofacial surgeons, paediatricians, orthodontists, paediatric dentists, dental hygienists, speech and language specialists, otolaryngologists (ENT specialists), audiologists (hearing specialists), genetic counsellors, nurse team co-ordinators, social workers, etc. The care that individuals born with cleft receive or can access across their life course also depends on many factors, including social determinants of health, parental knowledge and beliefs, distance from a clinic, financial protection from the cost of treatment, etc. Not receiving the full spectrum of treatment, especially nutritional support, speech therapy and oral healthcare, can have a significant adverse effect on the child's quality of life and even result in social exclusion continuing into adulthood.



-
2. Early surgical and healthcare intervention provides the best opportunity for the individual to live a full and fulfilling life. Additionally, the economic savings in terms of disability-adjusted life years (DALYs) and healthcare services provided are significant. Therefore, comprehensive cleft care should be embedded in UHC benefit packages and government should ensure financial protection from, and equitable access to, good quality surgical interventions for all individuals born with cleft. Orofacial clefts are not minor congenital anomalies: if interventions are not provided in a timely way, the mortality rate is extremely high.
 3. Orofacial clefts have a significant impact on the social life of individuals and families with a resultant effect on their well-being and oral health-related quality of life. Individuals with cleft rarely escape dental complications. Clefts can be associated with missing or extra teeth, malformed teeth and facial structures, and malocclusion. Therefore, individuals born with cleft tend to have poorer oral health, and more tooth decay and loss. These differences can be attributed to multiple factors including dry mouth, caused by specific mouth-breathing habits, less natural cleaning of the teeth due to the morphology caused by the cleft, different diet or feeding habits, dental malformations, increased consumption of sweetened medications, increased food clearance time after eating, and more carious bacteria in the oral cavity. Even those who undergo cleft surgery are often at an increased risk for dental caries, periodontal disease, and other oral health and well-being issues as they grow and develop. Therefore, people born with cleft require regular oral healthcare to ensure adequate monitoring, education, support, and treatment to prevent these oral diseases and achieve the highest possible quality of life.
 4. The interdisciplinary cleft care team, including oral and non-oral health professionals, should be committed to contributing and maintaining a longstanding expertise in preventing oral diseases. It is important that the whole cleft care team understands oral diseases and how to prevent them. It is essential that all healthcare providers can communicate effectively with individuals and caregivers, assess the risks, and refer them to other services when appropriate so that individuals receive adequate treatment and support. Therefore, all healthcare providers should be well educated on the health implications of cleft, the latest basic oral healthcare procedures, including the FDI and Smile Train guidelines: Oral Health in Comprehensive Cleft Care; Guidelines for Oral Health Professionals and the Wider Cleft Care Team, in order to monitor and maintain the oral health of people born with cleft across their life course.
 5. As orofacial clefts form during the embryonic development of a child at the time when the mother may not be aware of the pregnancy, a common risk factor approach is needed during antenatal care services and also as part of population-wide prevention policies. Tackling the environmental factors of orofacial clefts and other NCDs, including through tobacco and alcohol control policies and adequate nutritional supplementation during pregnancy, is crucial. Additionally, maternal, newborn and child health strategies need to incorporate comprehensive cleft care and ensure equitable access to these services.

REFERENCES

1. CDC. Facts about Cleft Lip and Cleft Palate | CDC [Internet]. Centers for Disease Control and Prevention. 2020 [cited 2021 May 5]. Available from: <https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html>
2. Mai CT, Isenburg JL, Canfield MA, et al. National population-based estimates for major birth defects, 2010-2014. *Birth Defects Res.* 2019 Nov 1;111(18): 1420-35.
3. Dixon MJ, Marazita ML, Beaty TH, Murray JC. Cleft lip and palate: understanding genetic and environmental influences. *Nat Rev Genet.* 2011 Mar;12(3): 167-78.
4. National Center on Birth Defects and Developmental Disabilities Home | NCBDDD | CDC [Internet]. [cited 2021 May 5]. Available from: <https://www.cdc.gov/ncbddd/index.html>
5. Draft Global Strategy on Oral Health [Internet]. Geneva: World Health Organisation; [cited 2021 Aug 27]. Report No.: 09 August 2021. Available from: [https://cdn.who.int/media/docs/default-source/searo/india/health-topic-pdf/noncommunicable-diseases/draft-discussion-paper--annex-3-\(global-strategy-on-oral-health\)-.pdf](https://cdn.who.int/media/docs/default-source/searo/india/health-topic-pdf/noncommunicable-diseases/draft-discussion-paper--annex-3-(global-strategy-on-oral-health)-.pdf)
6. Murray JC. Gene/environment causes of cleft lip and/or palate. *Clin Genet.* 2002 Apr;61(4): 248-56.
7. Cooper ME, Stone RA, Liu Y, Hu DN, Melnick M, Marazita ML. Descriptive epidemiology of nonsyndromic cleft lip with or without cleft palate in Shanghai, China, from 1980 to 1989. *Cleft Palate-Craniofacial J Off Publ Am Cleft Palate-Craniofacial Assoc.* 2000 May;37(3): 274-80.
8. Glick M, Williams DM, Kleinman DV, Vujcic M, Watt RG, Weyant RJ. A new definition for oral health developed by the FDI World Dental Federation opens the door to a universal definition of oral health. *Int Dent J.* 2016 Dec;66(6): 322-4.
9. Abbafati C, Machado DB, Cislighi B et al. Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet.* 2020 Oct;396(10258): 1204-22.
10. Wells M. Review suggests that cleft lip and palate patients have more caries. *Evid Based Dent.* 2014 Sep;15(3): 79.
11. McGrattan K, Ellis C. Team-Oriented Care for Orofacial Clefts: A Review of the Literature. *Cleft Palate-Craniofacial J Off Publ Am Cleft Palate-Craniofacial Assoc.* 2011 Oct 24; 50.
12. Eppley BL, Sadove AM. Management of alveolar cleft bone grafting--state of the art. *Cleft Palate-Craniofacial J Off Publ Am Cleft Palate-Craniofacial Assoc.* 2000 May;37(3): 229-33.
13. Chapple JR, Nunn JH. The oral health of children with clefts of the lip, palate, or both. *Cleft Palate-Craniofacial J Off Publ Am Cleft Palate-Craniofacial Assoc.* 2001 Sep;38(5): 525-8.
14. Mutarai T, Ritthagol W, Hunsrisakhun J. Factors Influencing Early Childhood Caries of Cleft Lip and/or Palate Children Aged 18 to 36 Months in Southern Thailand. *Cleft Palate-Craniofacial J Off Publ Am Cleft Palate-Craniofacial Assoc.* 2008 Oct 1;45: 468-72.
15. Nakashi J, Dixon-wood V, Nakashi JA, Dixon-Wood VL. In: *The craniofacial team: medical supervision and coordination* In: Bzoch KR, Ed *Communication disorders related to cleft lip and palate*. 3rd ed. Boston: College Hill Press, Brown and CO; 1989; 63-74.
16. Perillo L, d'Apuzzo F, Eslami S, Jamilian A. Cleft Lip and Palate Patients: Diagnosis and Treatment [Internet]. *Designing Strategies for Cleft Lip and Palate Care*. IntechOpen; 2017 [cited 2021 May 5]. Available from: <https://www.intechopen.com/books/designing-strategies-for-cleft-lip-and-palate-care/cleft-lip-and-palate-patients-diagnosis-and-treatment>
17. Kriens O, editor. *What is a cleft lip and palate?: a multidisciplinary update: proceedings of an advanced workshop*, Bremen 1987. Stuttgart: Thieme; 1989.
18. Butali A, Pagan-Rivera K, Dawson DV, et al. Descriptive Epidemiology of Orofacial Clefts in Africa Using data from 46,502 Smile Train Surgeries. 2017 May 1 [cited 2021 May 5]; Available from: <https://ir.unilag.edu.ng/handle/123456789/6635>

-
19. Kohli SS, Kohli VS. A comprehensive review of the genetic basis of cleft lip and palate. *J Oral Maxillofac Pathol JOMFP*. 2012;16(1): 64-72.
 20. Fk W, U H. An update on the aetiology of orofacial clefts. *Hong Kong Med J Xianggang Yi Xue Za Zhi*. 2004 Oct 1;10(5): 331-6.
 21. Alade AA, Buxo-Martinez CJ, Mossey PA et al. Non-random distribution of deleterious mutations in the DNA and protein-binding domains of IRF6 are associated with Van Der Woude syndrome. *Mol Genet Genomic Med*. 2020;8(8): e1355.
 22. Gowans LJJ, Adeyemo WL, Eshete M, , et al. Association Studies and Direct DNA Sequencing Implicate Genetic Susceptibility Loci in the Etiology of Nonsyndromic Orofacial Clefts in Sub-Saharan African Populations. 2016 Oct 1 [cited 2021 May 5]; Available from: <https://ir.unilag.edu.ng/handle/123456789/6631>
 23. Kawalec A, Nelke K, Pawlas K, Gerber H. Risk factors involved in orofacial cleft predisposition – review. *Open Med*. 2015 Feb 5;10(1): 163-75.
 24. Glick M, Williams DM, Ben Yahya I, et al. *Vision 2030: Delivering Optimal Oral Health for All*. Geneva: FDI World Dental Federation; 2021.
 25. American Academy on Pediatric Dentistry Clinical Affairs Committee, American Academy on Pediatric Dentistry Council on Clinical Affairs. Policy on management of patients cleft lip/palate and other craniofacial anomalies. *Pediatr Dent*. 2008 2009;30(7 Suppl): 238-9.
 26. Al-Dajani M. Comparison of dental caries prevalence in patients with cleft lip and/or palate and their sibling controls. *Cleft Palate-Craniofacial J Off Publ Am Cleft Palate-Craniofacial Assoc*. 2009 Sep;46(5): 529-31.
 27. Sundell AL, Nilsson A-K, Ullbro C, Twetman S, Marcusson A. Caries prevalence and enamel defects in 5- and 10-year-old children with cleft lip and/or palate: A case-control study. *Acta Odontol Scand*. 2016;74(2): 90-5.
 28. Dental concerns of children with lip cleft and palate - a review. *J Pediatr Neonatal Care* [Internet]. 2018 Jul 19 [cited 2021 May 5]; Volume 8(Issue 4). Available from: <https://medcraveonline.com/JPNC/JPNC-08-00333.pdf>
 29. Cheng LL, Moor SL, Ho CTC. Predisposing factors to dental caries in children with cleft lip and palate: a review and strategies for early prevention. *Cleft Palate-Craniofacial J Off Publ Am Cleft Palate-Craniofacial Assoc*. 2007 Jan;44(1): 67-72.
 30. The Value of Preventive Oral Health Care | College of Dentistry | University of Illinois at Chicago [Internet]. [cited 2021 May 5]. Available from: <https://dentistry.uic.edu/news-stories/the-value-of-preventive-oral-health-care/>
 31. Xu K, Evans DB, Kawabata K, Zeramardini R, Klavus J, Murray CJ. Household catastrophic health expenditure: a multicountry analysis. *The Lancet*. 2003 Jul 12;362(9378): 111-7.
 32. Mossey PA, Modell B. Epidemiology of oral clefts 2012: an international perspective. *Front Oral Biol*. 2012;16: 1-18.
 33. Molina-Solana R, Yáñez-Vico RM, Iglesias-Linares A, Mendoza-Mendoza A, Solano-Reina E. Current concepts on the effect of environmental factors on cleft lip and palate. *Int J Oral Maxillofac Surg*. 2013 Feb;42(2): 177-84.
 34. Oginni FO, Adenekan AT. Prevention of oro-facial clefts in developing world. *Ann Maxillofac Surg*. 2012;2(2): 163-9.
 35. Poenaru D, Lin D, Corlew S. Economic Valuation of the Global Burden of Cleft Disease Averted by a Large Cleft Charity. *World J Surg*. 2016 May;40(5): 1053-9.
 36. Carlson LC, Hatcher KW, Tomberg L, Kabetu C, Ayala R, Vander Burg R. Inequitable Access to Timely Cleft Palate Surgery in Low- and Middle-Income Countries. *World J Surg*. 2016 May 1;40(5): 1047-52.
 37. Seventy-fourth World Health Assembly WHA74.5 [Internet]. Geneva: World Health Organisation; 2021 May. Available from: https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R5-en.pdf

