# 認識唇顎裂和相關的顱顏缺陷

About Cleft & Related Craniofacial Anomalies

# 何謂唇顎裂? What is Cleft lip and Palate?

#### 甚麼是唇顎裂?

唇顎裂是最常見的一種先天性顱顏缺陷,亦是最能夠醫治的一種缺陷。若患者在合適的年齡得到適切的治療,他們的外貌、能力及社交與其他人無異。 在亞洲地區約每六百至七百名新生嬰兒便有一名患者。

## 唇顎裂的類別

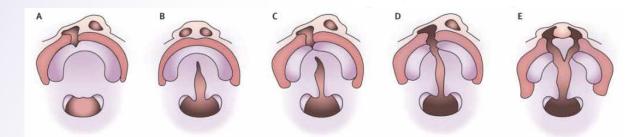
唇顎裂視乎裂縫的位置和程度大致分為數個類別, 請看以下轉載圖解。

#### What is Cleft Lip & Palate?

Cleft Lip and Palate is a very common and most curable congenital deformity. If the patients receive appropriate treatments at the right time, they can rehabilitate. Their capability and social life are no different from other people.

#### **Different Types of Cleft Lip and Palate**

There are different types of cleft lip and palate as follows (image from internet):



- A 唇裂及牙床不全裂
- B 不完全顎裂
- C唇裂、牙床裂及不完全顎裂
- D單側唇顎及牙床骨裂
- E 雙側唇顎及牙床骨裂

- A. Complete cleft lip & incomplete cleft alveolar
- B. Incomplete cleft palate
- C. Complete cleft lip & cleft alveolar with incomplete cleft palate
- D. Complete unilateral cleft lip, cleft alveolar & cleft palate
- E. Complete bilateral cleft lip, cleft alveolar & cleft palate

#### 成因 Causes

#### 傳因素影響:

- 1. 環境因素
- 病毒感染 (如德國麻疹)、服用某些藥物 (如抗癲癇、抗癌、類固醇藥物等)、X 光幅射線照射、營養不平衡

#### 2. 遺傳因素

- 由不正常的因子、染色體或細胞形成。
- 若父母本身其中一位有唇顎裂或生有一名唇顎裂子女者・得病的機會高達二十分之一;若雙親是唇顎裂患者或育有兩名唇顎裂子女・得病的機會更高達四分之一。

Most of the causes are unknown, some are due to the following environmental or genetic factors:

#### 1. Environmental Factors

- Viral infection (such as German measles)
- Drug effect (such as anti-convulsion, cytotoxic drugs, steroid)
- Exposure to X-ray during pregnancy
- Nutrition imbalance

#### 2. Genetic Factors

- Formed by abnormal factors, cells or chromosomes.
- If one of the parents has cleft lip or palate, or has one child with this defect, the chance that the next child will be affected can be as high as 5%; If both parents are patients or have two children with this defect already, the risk may rise up to 25%.

# 唇顎裂療程 Treatments for Clefts

在本港·唇顎裂的軟組織修復手術(包括:補唇、補顎、咽喉手術及成人唇鼻手術)在不同的公立 醫院會由不同的外科部門處理·分別為:(1)整形及重建外科或(2)小兒外科+耳鼻喉科·由於兩者的治療模式有所不同·所以為方便大家辨識·以下以「治療路徑1」及「治療路徑2」區分。

唇顎裂患者需在不同年齡接受醫治,治療以「外科手術」為主,分兩個階段進行,即:第一期和第二期手術治療,詳情如下:

In Hong Kong, soft tissue surgeries for cleft anomalies such as cleft lip repairs, cleft palate repairs, pharyngoplasty and adults' lip & nose revision surgeries at different public hospitals are provided by different surgical specialties, namely (1) Plastic & Reconstructive Surgery or (2) Paediatric Surgery + Otolaryngology. As there are two different modes of treatment, to distinguish between them, 'Treatment Way 1' & 'Treatment Way 2' are applied in the below.

Cleft lip and palate patients have to receive treatments at different ages. The treatments are mainly surgeries, providing in the primary & secondary stages as follows:

療程 Phase	年齢 Age	治療概要 Treatments	醫院及負責專科 Hospital & Responsible Specialty	
			治療路徑 1 Treatment Way 1	治療路徑 2 Treatment Way 2
	*	\1/*	瑪麗 / 廣華 / 屯門醫院 QMH / KWH / TMH	兒童醫院 CH
	0-3 個月 0-3 months	非手術性唇鼻矯形 (協會提供) Non-surgical lip & nose correction ( Providing by HKACLP )	提供鼻顎托 Provide NAM	提供鼻顎托 Provide NAM
第一期手術 Primary surgeries	3個月 3 months	• 裂唇修補手術 Repair of cleft lip	整形及重建外科 Plastic &	小兒外科
	1歲 1 year	• 裂顎修補手術 Repair of cleft palate	Reconstructive Surgery	Paediatric Surgery
第二期手術 Secondary surgeries	約 10 歲 Around 10 yrs	牙槽植骨手術     Alveolar bone graft	口腔頜面外科 Oral & Maxillofacial Surgery	口腔領面外科 Oral & Maxillofacial Surgery
	18 歲及以上 18 yrs and above	颚骨矯正手術 - 以改善因上顎發育不 足而出現的牙齒倒及問題(如有需要) Jaw surgery for secondary cleft maxillary deformities (if required)		
	18 歲及以上 18 yrs and above	唇鼻整形手術 - 改善唇鼻外觀和功能 Surgical revisions for lip & nose deformities for aesthetically and functional purposes	整形及重建外科 Plastic & Reconstructive Surgery	約 2014 由耳鼻喉 科開始提供鼻重修 手術 Otolaryngologists provide nose surgeries since 2014

- 上表治療路徑以「完全唇顎裂」為例,其餘「唇裂、顎裂或不完全唇顎裂」只需按個別情況接受部份治療。
- 協會為 7-12 歲唇顎裂患童提供【早期矯齒治療】·以改善他們的牙齒倒及問題·亦可能減低他們日後顎骨矯正手術的複雜程度·輕症者甚或可避免這手術。
- 患者需由耳鼻喉科跟進中耳炎及耳積水問題 · 及按個別需要接受言語治療 。
- 唇顎裂是一種先天性顏面口腔的缺陷,患者不單只需要接受第一期的補唇和補顎手術,他們成年後亦需要接受第二期唇鼻整形手術, 家長在選擇治療服務時必需一併考慮。
- The above treatment is for patients with complete clefts, those patients with incomplete clefts only need part of the above treatment.
- HKACLP provides Early Orthodontic Treatment for cleft lip & palate children between 7-12 years old so as to minimize their underbite problem, and thus consequently the complexity of their future jaw surgery will be alleviated, or can even avoid it.
- If required, the patients may receive speech therapy, and seek for Otolaryngologists's treatment for ear infection and fluid in middle ear(s)
- Cleft lip and palate is a kind of orafacial anomalies, the patients not only need Primary Treatment but also require the Secondary one. Therefore, when choosing treatment service for their affected babies, the parents should consider the entire treatment course, not just the primary one.

(以上資料只供參考·如有疑問·請向個別醫院查詢 The above information is only for reference. For details, please inquire individual hospital.)

# 唇顎裂的影響 Problems of Cleft Lip and Palate

#### 初生期

- 外貌不正常
- 餵哺困難,容易哽嗆

## 成長期

- 容易有中耳炎、耳積水問題
- 可能說話會有鼻音
- 牙槽裂隙附近會有缺齒及牙齒錯位情況
- 上顎發育不足、中間臉部凹陷、上下牙齒倒岌
- 第二期唇鼻外觀和功能問題

#### <u>Infancy</u>

- Abnormal appearance
- Difficult in feeding

#### **Childhood and Up**

- Ear infections & fluid builds up in the middle ear
- Some misplaced and missing teeth
- Insufficient growth of upper jaw, dented mid face and underbite problem
- Secondary lip and nose deformities

# 第一期治療 Primary Treatment

## 補唇手術 Surgical Repair for Cleft Lip

補唇手術在患兒 3 個月大時進行·幫助患兒修補缺裂的 上唇·改善外觀和上唇功能。 Cleft lip repair will be arranged between 3 months. After the surgical repair, the affected babies may have normal appearance and lip function.







(以上補唇手術由整形及重建外科醫生提供 the above cleft lip repairs provided by Plastic & Reconstructive Surgeons)

## <u>補顎手術 Surgical Repair for Cleft Palate</u>

補顎手術在患兒 12 個月大時進行,幫助患兒修補缺 裂的上顎,以恢復正常的上顎結構,幫助他們進食 和開展語言。

Cleft palate repair will be arranged around 1 year of age. After the surgical repair, the affected babies may have normal roof of the mouth and swallowing function.



(以上補顎手術由整形及重建外科醫生提供 the above cleft palate repairs provided by Plastic & Reconstructive Surgeons)

# 第二期唇顎裂治療

#### **Secondary Treatments**

## 牙槽植骨手術 Alveolar Bone Graft

牙槽植骨手術的目的是修補牙槽縫隙、接合牙槽骨、幫 助犬齒長出,以利日後齒列矯正或假牙裝置,手術並可 改善鼻底對稱性。

The purpose of alveolar bone grafting surgery is to repair the alveolar gap, join the alveolar bone, and help the canine teeth erupt, so as to facilitate future orthodontics or denture installation. The surgery can also improve the symmetry of the nasal floor.

# 顎骨矯正手術 Orthognathic Surgery

由於唇顎裂缺陷,患者的上顎發育會比較慢,容易出現 上下牙齒倒及問題,他們會在發育完成(約18歲)接 受由口腔領面外科醫生提供的顎骨矯正手術。如兔唇裂 顎患童在6-12歲間接受早期矯齒治療,能「及早」和「有 效」改善他們的牙齒不咬合問題,收窄上下牙齒倒的程 度,幫助他們進食和說話,改善他們的外觀,亦可減低 他們日後顎骨矯正手術的複雜程度、輕症者甚或可避免 這手術。

Due to cleft anomalies, the growth of the patients' upper jaw may be affected, resulting in retrusive upper jaw and underbite problem. They may need orthognathic surgery provided by Oral & Maxillofacial Surgeon around 18 years of age. Early Orthodontic Treatment during the age 6-12 while the jaw is still growing may help effectively to correct cleft lip & palate children's underbite problem so that consequently the complexity of jaw surgery will be alleviated, or can even avoid it.

# 成人整合式唇鼻整形手術 Combined Lip & Nose Revision Surgery for Adults

患者隨著成長,輪廓逐漸分明,唇和鼻的外觀及功能可 能不夠理想,如:患側鼻部扁塌、唇鼻外形不對稱、唇 部閉合不佳等,這些典型唇顎裂特徵令患者感到難堪和 自卑,同時亦容易遭到他人的歧視和排斥,甚至影響社 交和求職。「整合式唇鼻整形手術」的目的是幫助患者 改善唇鼻外觀、功能、發音、進食及社交,這項手術對 患者非常重要,是他們期待多年可改善面容差異的手 術!

As a cleft lip and palate patient grows up, he may have developed secondary cleft lip and nasal deformity such as tight upper lip, irregular lip scars, asymmetric upper lip, widened and flattened nostril(s) etc. These typical characteristics of clefts make the patients feel embarrassed and inferior. At the same time, they are also prone to discrimination and rejection by others, and even affect their social interaction and job finding. Combined Lip and Nose Reconstructive Surgery helps the patients improve their appearance, lip & nose function, speech and eating. This surgery is very important to the patients who have been longing for years to eliminate their facial differences!





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(左邊6位成人患者的唇鼻整形手術由整形及重 建外科醫生提供。自 1970 年中起,瑪麗醫院、廣 華醫院 及 屯門醫院 的 整形及重建外科部先後開 始提供全程完整的唇顎裂及顱顏缺陷的綜合治療。

The Lip & Nose Revision Surgeries for the 6 adult patients on the left hand side are provided by Plastic & Reconstructive Surgeons. Since mid-1970, Plastic & Reconstructive Surgery Departments of Queen Mary Hospital, Kwong Wah Hospital and Tuen Mun Hospital have begun one after the other providing complete treatment for the patients with cleft & craniofacial anomalies.)

近年·整形及重建外科醫生在患童約 10 歲時為他們提供輕微唇鼻整形手術·以幫助他們較容易過渡青春期。 In recent years, Plastic & Reconstructive Surgeons provides minor lip & nose revision surgeries for cleft lip and palate children around 10 years of age in order to enable them easier transition to puberty.







## 唇顎裂綜合醫療團隊成員

唇顎裂患者由初生至成年階段需要接受由幾個不同 專科部門提供的綜合治療·綜合醫療團隊的成員和 職責如下:

## 整形及重建外科醫生

專業負責唇顎裂和顱顏缺陷患者的整形及重建手術,病人並無年齡上限,全程跟進患者的治療直至完全康復,他們提供手術包括:

- 為 3 個月大的患兒提供第一期補唇手術;
- 為 12 個月大的患兒提供第一期補顎手術;
- 如有需要·為8-12歲患童提供輕微的唇鼻整形、
   改善顎咽閉合不全等手術;及
- 為成人患者提供第二期唇鼻整形及整容手術。
- 為皮爾羅賓症、巨口症、小耳症等顱顏缺陷患者提供修補及重建手術。

或

#### 小兒外科醫生

專業負責小兒外科手術·病人年齡上限至 16 歲·提供手術包括:

- 第一期補唇及補顎等手術。
- 轉介 16 歲及以上的患者給耳鼻喉科醫生以跟進 鼻部重修手術。

#### Multidisciplinary Team Members

Patients with cleft lip and palate require from babyhood to adulthood a team approach for their treatment, comprised of several specialists. The multidisciplinary team members are as follows:

## Plastic & Reconstructive Surgeons

Professionally responsible for reconstructive surgeries for the patients with cleft & craniofacial anomalies. Their patients have no upper age limit. They follow up the patients from newborn to adulthood up till full recovery. The surgical treatments they provide:

- Primary Surgeries cleft lip repair at 3 months old and cleft palate repair at 12 months old;
- If required, provide for affected children minor lip & nose revision, pharyngoplasty for nasal speech etc.
- Secondary Surgeries lip & nose revisions for the teenage and adult patients.
- provide reconstructive surgeries for the patients with Pierre Robin Sequence, Macrostomia, Microtia etc.

or

#### Pediatric Surgeons

Professionally responsible for the surgeries to pediatric patients up to the age of 16, providing surgeries as follow:

- Primary Surgeries cleft lip repair at 3 months old and cleft palate repair at 12 months old etc.
- Referred the patients over 16 years old to otolaryngologists for nose surgery.

### 矯齒科醫生

- 為 7-12 歲唇顎裂患童擴張上牙槽、引導上顎骨 向前生長及矯正錯位牙齒,以改善他們因顎裂 而引致的上下牙齒倒及問題。
- 另,如有需要,為約 16 歲及以上的患者提供配 合顎骨矯正手術的「術前」和「術後」矯齒。

## 口腔領面外科醫生

#### 為唇裂顎患者提供:

- 為約 10 歲的患童提供牙槽植骨手術;及
- 為 18 歲及以上的患者提供顎骨矯正手術 (如已 接受早期矯齒治療後仍有上下牙齒倒及問題)。

# Oral & Maxillofacial Surgeons

Provide alveolar bone graft surgery for child patients between 8-10 years; and

For the child patients aged 7-12 years old, they help

to expand the upper alveolar, divert the upper jaw

to a more forthward direction and align the crooked

teeth, so as to improve their underbite problems; and

Besides, if required, they provide for patients aged 16 years and above "pre-operative" and "post-operative"

orthodontics in conjunction with orthognathic surgery.

Besides, if required, provide orthognathic surgery for patients over 18 year old to correct their secondary cleft maxillary deformities.

## 耳鼻喉科醫生

- 跟進唇顎裂患者的中耳炎及中耳積水問題
- 近年有個別公院的耳鼻喉科醫生開始提供唇顎 裂成人患者的第二期鼻部重修手術,與及小耳 症患者的耳廓重建手術。

#### 言語治療師

- 評估初生患兒餵食
- 為2歲及以上唇顎裂患兒的提供言語治療

# Otolaryngologist

Orthodontists

- Following up patients' ear infections & alleviate fluid build-up in middle ears to restore hearing; and
- In recent years, otolaryngologists of individual public hospital provide nose surgeries for adult patients with clefts and auricular reconstruction for patients of microtia.

## Speech Therapist

- Assess affected babies's feeding; and
- Provide speech therapy for child patients over 2 years of age.

# 其他與唇顎裂相關的顱顏缺陷

## **Cleft Related Craniofacial Anomalies**

其他與唇顎裂相關的顱顏缺陷包括:皮爾羅賓症、 巨口症、小耳症等。

There are some cleft related craniofacial anomalies, namely Pierre Robin Sequence, Macrostomia, Microtia etc.







皮爾羅賓症 Pierre Robin Sequence

巨口症 Macrostomia

小耳症 Microtia

(以上顱顏缺陷重建手術由整形及重建外科醫生提供 The above surgeries provided by Plastic & Reconstructive Surgeons)

# 在治療過程中,協會給予家長和患兒/患者以下的幫助:

During the course of treatment, HKACLP offers help to the parents & children/adult patients as follows:

## 懷孕期

- 懷孕家長在線支援
- 輔導及面談服務
- 餵哺患兒訓練
- 促進家長交流分享、自助互助
- 提供本港公營治療服務資料

## 患兒出生後

- 非手術性唇鼻矯形
- 提供患兒專用奶瓶和護理用品
- 患兒照顧訓練班
- 提供術後手肘固定套借用
- 提供手術前及後照顧資料
- 疤痕按摩工作坊

## 成長中患兒及成年患者

- 跟進式矯形鼻托服務
- 駐會言語治療服務及家長訓練班
- 兒童矯齒治療服務
- 青年矯齒資助計劃
- 各項手術術前預備工作坊
- 醫學及專題講座
- 成人患者二期治療諮詢
- 慈善治療計劃及愛延續唇顎裂治療基金

還有·協會的「伴你同行 - 唇顎裂患兒家庭 支援服務」的義工將會全程陪伴及幫助每一 個患者家庭。

# 其他工作

除以上直接服務外,本會更致力-

- 保障病人權益
- 為患者爭取最合適的公營治療服務
- 透過以下宣傳及教育工作以增加大眾認 識唇顎裂及促進社會共融
  - 學校生命教育
  - 社區展覽
  - 協會網頁及社交平台

## **During Pregnancy**

- Online Support for Pregnant Mothers
- Counselling Service
- Newborn Babies Feeding Workshop
- Promote sharing, mutual help & support among parents
- Provide information about public treatment services in Hong Kong

#### **After Birth**

- Non-surgical lip & nose correction
- Provision of feeding bottles & caring items
- Caretaking course for new parents
- Providing postoperative restraints for babies after cleft lip or cleft palate repair
- Providing pre- & post-operation support
- Scar massage workshop

#### For Children & Adults

- Nasal Splint Service
- Resident Speech Therapy & Parents Training Course
- Orthodontic Treatment for Children with Clefts
- Orthodontic Treatment Subsidy Project for Youngsters with Clefts
- Medical and Special Topic Seminars
- Preparatory Workshops for different surgeries/treatments
- Adults' enquiry for secondary treatments
- Charity Treatment Project & Let Love Continue Cleft Lip and Palate Treatment Fund

Besides, HKACLP's volunteers of 'Be with You Project' will help and support every family throughout the course of treatment over 20 years.

#### **Other Commitments**

Apart from direct services, HKACLP is also committed to -

- Protect patients' rights and interests;
- Strive for the most appropriate public treatment services for the patients;
- Through publicity and education to increase the general public's understanding of cleft anomalies and enhance social inclusion
  - School life education activities
  - Community Exhibitions
  - Official website & social platforms