



An-Najah National University
Faculty of Graduate Studies

**MATERNAL AND PATERNAL RISK
FACTORS ASSOCIATED WITH
PALESTINIAN CLEFT PATIENTS**

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Dedication

This study is wholeheartedly dedicated to my beloved parent, who have been a source of inspiration for me and gave me strength when I thought of giving up, who continually provide their moral, spiritual, emotional, and financial support.

To my brothers, sisters, relatives, mentor, friends who shared their words of advice and encouragement to finish this study.

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I gratefully acknowledge the local medical team who works for many years to give the cleft patients the necessary care and surgeries.

Special thanks to my family and dear friends for their support and to be with me in achieving my dream of obtaining this master's degree.

Declaration

I, the undersigned, declare that I submitted the thesis entitled:

MATERNAL AND PATERNAL RISK FACTORS ASSOCIATED WITH PALESTINIAN CLEFT PATIENTS

I declare that the work provided in this thesis, unless otherwise referenced, is the researcher's own work, and has not been submitted elsewhere for any other degree or qualification.

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Date:

19/2/2022

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MATERNAL AND PATERNAL RISK FACTORS ASSOCIATED WITH PALESTINIAN CLEFT PATIENTS

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ABSTRACT

Background: Cleft lip with or without cleft palate (CL/P) is the most common orofacial anomaly in newborns and the incidence varies based on ethnicity, etiology of

Clefts seem to be related to many factors including environmental, genetic, and geographic factors. Identification of risk factors can lead to prevention and decreasing the cleft incidence rate. The aim of this study is to identify the risk factors associated with Palestinian CL/P.

Methods: This study is a cohort retrospective, descriptive, non-randomized study using a survey administered to parents of children with congenital anomalies in the West Bank Hospitals.

Results: Out of 543 patients, the highest clefting rate was in southern regions, with no significant association between rural, urban or refugee status. (53%) of parents were consanguineous. Only 13% of patients had at least a first-degree blood relative with a cleft patient and 43% with other relatives. 95% of patients' mothers received prenatal care and only 14% of clefts appeared in ultrasound image, 5% of mothers took folic acid (FA) before pregnancy and 60% took FA during pregnancy. The smoking rate for mothers of children with clefts was 4%, but 64% were exposed to second-hand smoking.

Conclusion: Consanguinity, maternal exposure to smoking and lack of FA intake before and during pregnancy appear to be risk factors of carrying cleft infants. However, sex, refugee status, or civil status were not significantly associated with an increased risk of CL/P. Further studies and education programs were required.

Keywords: Orofacial anomaly, Cleft Lip and Palate, Risk factors, Palestine.

Chapter One

Introduction

1.1 Introduction

Cleft lip with or without cleft palate (CL/P), is the most common Orofacial Anomaly (OA) in newborns, and the incidence varies based on ethnicity.(Derijcke, Eerens et al. 1996) World-wide, the incidence of CL/P is 1.42 per 1000 live births. The highest incidence of CL/P is observed in Native Americans (3.6 per 1000) and Asians (2.1 per 1000), the lowest rate among Africans (0.41 per 1000). Most of the population In the Middle East is ethnically classified as Caucasian, and the incidence is approximately 1 per 1000.(Kumar, Hussain et al. 1991, Borno, Hussein et al. 2014)

The researchers have investigated clefting rates in Iran is (1.03 per 1000)(Rajabian and Sherkat 2000), the highest reported incidence rate for Arabs in Saudi Arabia is (2.19 per 1000)(Borkar, Mathur et al. 1993), Israel (0.7 per 1000), Jordan (1.39 per 1000), the exact incidence of CL/P among Palestinians living in the Palestinian territories (West Bank and Gaza) is unknown.(Al Omari and Al-Omari 2004, Borno, Hussein et al. 2014, Shapira, Haklai et al. 2014) Most of CL/P patients suffer from feeding difficulties in infancy, hearing, speech, dental, social and psychological problems due to the facial deformity when they grow older.(Dixon, Marazita et al. 2011) Gender, geographical location, nationality, nutritional, tobacco use, use of anti-epileptic drugs, alcohol consumption, low birth weight, pesticides, and contaminated water sources have all been hypothesized as factors increasing the incidence of CL/P in newborns.(Murray 2002, Gundlach and Maus 2006, Romitti, Herring et al. 2007, Cech, Patnaik et al. 2008, Golalipour, Kaviany et al. 2012) The variability of CL/P incidence is attributed to differences in environment, exposure to stressors, and genetics across populations.(Saxen 1975, Tyan 1982, Vanderas 1987, Matthews 2011)

The prevalence and incidence of CL/P in the Palestinian territories may be higher than in surrounding countries. In the Palestinian territories, the population has a high rate of consanguinity, which is thought to increase the risk of congenital anomalies associated with syndromes.(Bromiker, Glam-Baruch et al. 2004) Some reports indicate that 60% of couples in the territories are first- and second-degree cousins,(A 2001) while consanguineous marriages make up 50% of marriages in other parts of the Middle East.(Mehndiratta, Paul et al. 2007) In addition, chronic stress is a factor that is linked to an increased risk for this condition.(Matthews 2011)

Maternal dietary intake plays a significant role in babies born with CL/P.(Krapels, Vermeij-Keers et al. 2006) Using of multivitamins is reported to reduce the risk of CL/P in most studies (Loffredo, Souza et al. 2001, Badovinac, Werler et al. 2007, Wilcox, Lie et al. 2007, Johnson and Little 2008, Jia, Shi et al. 2011). Folic acid supplementation is shown to decrease the risk of neural tube defects,(De-Regil, Pena-Rosas et al. 2015) but its effect on CL/P remains inconsistent.(Badovinac, Werler et al. 2007, Johnson and Little 2008, Rozendaal, van Essen et al. 2013, De-Regil, Pena-Rosas et al. 2015)

1.2 Significance of the study

CL/P patients are well studied in many countries including risk factors, prevention, and treatments. However, the area is under-studied in Palestinian society and this study will help to understand the risk factors associated with Palestinian CL/P patients.

1.3 Aim of study

The aim of this study is to identify the maternal and paternal risk factors associated with Palestinian CL/P patients to avoid and reduce the cleft's incidence rate by focusing in three major risk factors which are consanguinity, smoking during pregnancy, FA intake before and during pregnancy. Also, this study aims to improve the identification of clefts by ultrasound imaging.

1.4 Literature Review

1.4.1 Background

CL/P known as Orofacial Clefts (OC) is a group of conditions that includes cleft of the lip (CL), cleft of the palate (CP) or cleft lip and palate (CLP).(2009, Watkins, Meyer et al. 2014) Cleft lip with or without cleft palate (CL/P) is a result of facial tissues not fusing properly during fetal development. The cause of most clefts is unknown in 80% of cases.(2009)

CL contains a complete or incomplete opening in the upper lip extending into the nose; the CL may be unilateral or bilateral. CP occurs when the roof of mouth contains an opening into the nose. (2009)

World-wide, the incidence of CL/P is 1.42 per 1000 live births. The highest incidence of CL/P is observed in Native Americans (3.6 per 1000) and Asians (2.1 per 1000), while the

lowest rate is among Africans (0.41 per 1000). Most of Middle East population is ethnically classified as Caucasian, and the incidence is approximately 1 per 1000.(Kumar, Hussain et al. 1991, Borno, Hussein et al. 2014)

CL/P can cause feeding problems, speech and hearing problems, ear infections, dental problems, social, and psychological problems. (2009, Dixon, Marazita et al. 2011) Gender, geographical location, nationality, nutritional, tobacco use, use of anti-epileptic drugs, alcohol consumption, low birth weight, pesticides, and contaminated water sources have all been hypothesized as factors increasing the incidence rate of CL/P in newborns.(Murray 2002, Gundlach and Maus 2006, Romitti, Herring et al. 2007, Cech, Patnaik et al. 2008, Golalipour, Kaviany et al. 2012) CL/P can be often detected with an ultrasound image during pregnancy.(Loozen, Maarse et al. 2015)

CL can be treated during the first few months of age, and CP surgery is usually performed before the eighteen months of age. (2009)

1.4.2 Diagnosis

OC, especially CL/P can be diagnosed during pregnancy by a routine ultrasound. Prenatal ultrasound will often detect CL/P; however, CP is rarely identified by ultrasound.(November 2009) Several studies report that clefts can be detected at week 22 – 25 of pregnancy by axial 3-dimensional or 4-dimensional ultrasound.(Loozen, Maarse et al. 2015) CL/P can also be diagnosed at the time of birth by physical examination, sometimes certain types of cleft palate (for example: submucous cleft palate and bifid uvula) may not be diagnosed until later age.

1.4.3 Classification

CL/P is an umbrella term for OC, as it includes clefting of the upper lip, the maxillary alveolus, the hard palate, and the soft palate. The classification of a cleft in general includes: (Allori, Mulliken et al. 2017)

- Cleft Lip
- Cleft Lip and Alveolus
- Cleft lip, Alveolus, and Palate

- Cleft lip and palate
- Cleft Palate

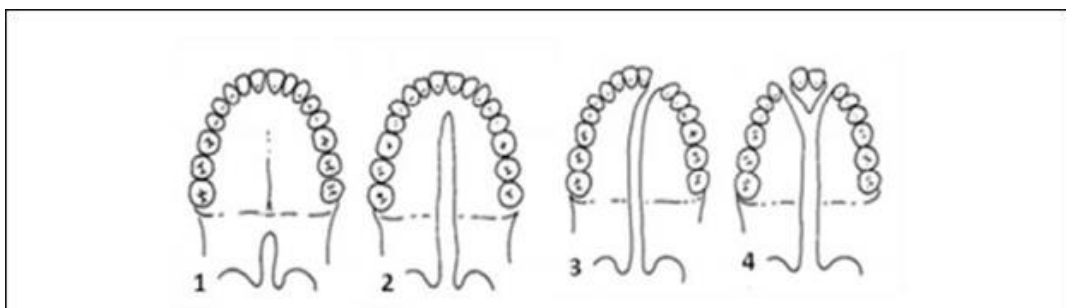
For many years, people caring for patients with CL/P have sought a comprehensive classification scheme for CL/P abnormalities. Veau (Veau and Borel 1931) proposed a method in 1931 for cleft classification. He categorized clefts into four classes (Figure 1.1).

1. Cleft soft palate alone
2. Cleft soft and hard palate
3. Complete unilateral cleft lip and palate
4. Complete bilateral clefts of the lip and palate.

This is the most popular, most simple classification and it is easy to use.

Figure 1.1

Veau's Classification of cleft lip and palate



In 1942, Fogh Anderson (Fogh-Andersen 1942) gave a cleft classification based on embryological development:

Group 1: Cleft lip (unilateral or bilateral).

Group 2: Cleft lip and cleft palate (unilateral or bilateral).

Group 3: Clefts of the lip and palate up to the incisive foramina.

In 1985, Kriens (Kriens 1989) proposed a simple palindromic system for cleft classification by using the letters LAHSHAL, the two sides of the lip (L), alveolus (A),

and hard palate (H) and the soft palate (S). By using upper- and lower-case letters to denote complete and incomplete clefts, respectively, this simple system can be used to categorize velar clefts (S), partial (hSh) and complete (HSH) clefts of the bony secondary palate, complete unilateral cleft lip and palate (LAHS or SHAL), incomplete clefts of the lip and alveolus (la or al), complete bilateral clefts of the lip and palate (LAHSHAL), and bilateral clefts with an incomplete cleft lip on one side (LAHSHA1 or 1AHSHAL). The main disadvantage of the LAHSHAL system is the inflexibility to describe a complex cleft malformation.

1.5 Epidemiology of Orofacial Clefts

CL/P is the most common orofacial congenital anomaly among live births.(Derijcke, Eerens et al. 1996) The prevalence of CL/P varies according to race/ethnicity, sex, and cleft type.(Al Omari and Al-Omari 2004) And depending on ancestry, geographic residential location, maternal and paternal age and socioeconomic status.(Wehby and Cassell 2010) The prevalence of CL/P shows wide racial variation, the lowest prevalence rate was among blacks and the prevalence is higher among Asians, while Caucasians is in the middle prevalence rate.(Al Omari and Al-Omari 2004)

World-wide, the incidence of CL/P is 1.42 per 1000 live births, the highest incidence of CL/P is observed in Native Americans (3.6 per 1000) and Asians (2.1 per 1000), and the lowest rate among Africans (0.41 per 1000). Most of Middle East population is ethnically classified as Caucasian, and the incidence is approximately 1 per 1000. (Kumar, Hussain et al. 1991, Borno, Hussein et al. 2014) For Caucasians, CL/ P is more common (1-2 per 1000 births) while CP is less common (1 per 1500–2000 births).(Lidral, Moreno et al. 2008)

The incidence rate of CL/P in Oman is (1.5 per 1000), Sudan (0.9 per 1000) and in Iran is (1.03 per 1000 births). (Aljohar, Ravichandran et al. 2008) Researchers has also investigated clefting rates in Israel (0.7 per 1000), Jordan (1.39 per 1000). The exact incidence of CL/P among Palestinians living in the territories (West Bank and Gaza) is unknown.(Al Omari and Al-Omari 2004, Borno, Hussein et al. 2014, Shapira, Haklai et al. 2014).

1.6 Risk Factors

The etiologies of CL/P are multi-factorial, including genetic and environmental risk factors have been identified as triggers for syndromic CL/P, while the etiology of non-syndromic CL/P remains unknown.(Dixon, Marazita et al. 2011) Gender, geographical location, nationality, nutritional, tobacco use, use of anti-epileptic drugs, alcohol consumption, low birth weight, Pesticides, and contaminated water sources have all been hypothesized as factors increasing the incidence rate of CL/P in newborns. (Murray 2002, Gundlach and Maus 2006, Romitti, Herring et al. 2007, Cech, Patnaik et al. 2008, Gosalipour, Kaviany et al. 2012)

Many studies have shown there is an association between maternal age and having a cleft baby.(Baird, Sadovnick et al. 1994, Figueiredo, Ly et al. 2015) Another study indicated that parental age showed that fathers 40 years or older have a 58% higher probability of having a child with a CP; the probability for mothers over 40 years is 28% higher for having a child with a CP and 56% higher for CL/P.(Herkrath, Herkrath et al. 2012)

Family history of clefting is also a strong risk factor for OC (Acuña-González, Medina-Solís et al. 2011, Rahimov, Jugessur et al. 2012, Burg, Chai et al. 2016). Also, many studies reported that there is an association between consanguineous marriage and incidence of clefts. (Shafi, Khan et al. 2003, Bromiker, Glam-Baruch et al. 2004, Jamilian, Sarkarat et al. 2017) Consanguineous marriages are an important factor contributing to increase of congenital malformations and subsequent morbidity and mortality among offspring.(Bromiker, Glam-Baruch et al. 2004) Studies also report the incidence of CL/P in infants born to smoking mothers during pregnancy is twice that of those born to non-smoking mothers (Johnston and Millicovsky 1985). Based-on a meta-analysis study, smoking is considered as the most consistent environmental risk factor associated with clefts, with odds ratios of 1.3 for CL/P and 1.2 for CP.(Little, Cardy et al. 2004)

1.7 Complications

In addition to cosmetic deformities, other potential complications that may associated with CL/P include :

- Feeding difficulties: Feeding difficulties occur more with CP patients. The cleft baby may be unable to suck properly because of the opening in the roof of the mouth.
- Ear infections and hearing loss: Ear infections are often due to a dysfunction of the tube that connects the middle ear and the throat. Recurrent infections can then lead to hearing loss.
- Speech and language delay: Due to the opening in the roof of the mouth and the lip, muscle function may be decreased, which can lead to a delay in speech or abnormal speech or abnormal voice.
- Dental problems: As a result of the cleft of the alveolus, teeth may not develop normally, and orthodontic treatment may be required.

1.8 Treatment

1.8.1 Cleft Lip Repair

CL surgery can be performed to close the cleft of the lip at the age of 3 months, with a preferred age of 10 weeks following the rule of 10s; the rule of 10s was coined in 1969 by Wilhelmmsen and Musgrave (10 weeks of age, 10 pounds of weight, and 10 g of hemoglobin). (Lydiatt, Yonkers et al. 1989)

1.8.2 Cleft Palate Repair

CP repair is performed surgically, usually performed between 9 and 18 months of age. Approximately 20–25% of cases require only one palate repair surgery to achieve a normal and non-hypernasal speech. However, combinations of surgical methods and repeated surgeries are often necessary as the child grows.(Schuchardt 1966)

1.8.3 Alveolar Bone Graft

At the ages of 1–7 years, the child with an alveolar cleft is regularly reviewed by the cleft team. By the age of 7 to 12 years, for children born with alveolar clefts, they may need to have an alveolar bone graft surgery, where autogenous cancellous bone from a donor site (often the pelvic bone) is transplanted into the alveolar cleft region.(Daljit S. Gill 2011)

1.8.4 Other Treatments

In addition to surgeries of repairing the cleft lip, palate and alveolus, cleft patients need other surgical and non-surgical management, which includes dental treatment, orthodontic treatment, speech and language therapy and psychological treatment.(Daljit S. Gill 2011)

Chapter Two

Methodology

2.1 Study Settings

The study was conducted in the government hospitals in the West Bank- Palestine.

2.2 Study Design

This study is a cohort retrospective, descriptive study that aims to determine the maternal and paternal risk factors associated with cleft patients in Palestine.

2.3 Target population

Palestinian parents of patients with CL/P and living inside Palestine.

2.4 Sampling

A convenient sample of all available records for CL/P patients and living inside Palestine.

2.5 Inclusion Criteria

Palestinian parents who have at least one patient with CL/P living inside Palestine and completed the survey.

2.6 Exclusion Criteria

Records for non-CL/P patients, non-completed surveys or not Palestinian parents were excluded in this research.

2.7 Data Collection

Samples was obtained based on the collected data by a non-randomized longitudinal study using a face-to-face interview with a 700 questions survey administered in Arabic to parents of children with congenital anomalies during screening or surgeries delegation in West Bank government's hospitals by trained volunteers' researchers fluent in Arabic and English, and uploaded to the Palestinian Congenital Anomalies Database (PCAD). PCAD was created in 2011 using a 700 questions survey administered in Arabic to parents of children with congenital anomalies, PCAD aims to

collect the cleft patients' data in a secured database and use this data for research or medical purposes. Survey consisting of 9 categories of questions: demographics, diagnosis, development, maternal information, paternal information, family information, general information, cleft repair historical information, and interventional information. PCAD is located in REDCap website, which is a mature, secure web application REDCap hosted by Cincinnati Children's Hospital for building and managing online surveys and databases.

2.8 Ethical Considerations

Approval for this study was obtained from An-Najah National University ethical committee. Informed consents were obtained from all participants prior to participation, and they were assured that all data collected would be confidential and available for the researcher only.

Chapter Three

Results

Out of 534 CL/P patients (51% females and 49% males), 53% of them were rural and 47% were urban, 23% of patients were refugees and only 22% of them are living inside refugee camps (Table 3.1). 44% of participants had CL/P, 32% had a CP and 23% had CL. Only 13% of these patients had at least one first-degree blood relative with a cleft, while 43% had another relative with a cleft (Figure 3.1).

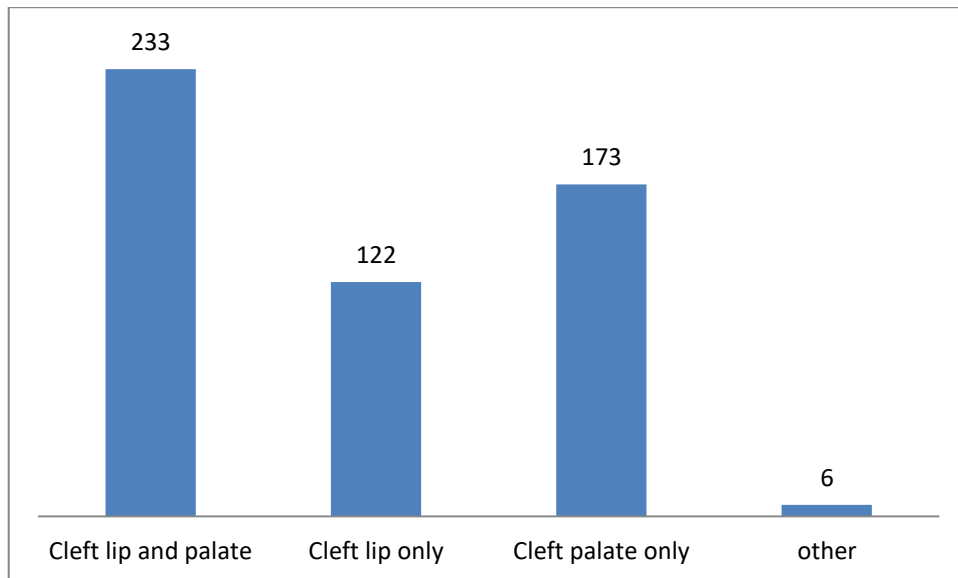
Table 3.1

Demographics

Gender	Male	261 (49%)
	Female	273 (51%)
Home	Rural	282 (53%)
	Urban	252 (47%)
Refugee status	Refugee	125 (23%)
	Not refugee	407 (77%)
Place of living of refugee patients	Inside refugee camp	28 (22%)
	Outside refugee camp	97 (78%)

Figure 3.1

Classification of Clefts



3.1 Distribution of Cleft Patients in West Bank Cities

The highest cleft incidence rate was in Hebron; 43% were residents in Hebron and 44% were originally from Hebron (Table 3.2).

Table 3.2

Distribution of Cleft Patients in West Bank Cities:

City name	Place of residence (Number)	Originally place of residence (Number)
Bethlehem	49 (9%)	42 (8%)
Hebron	230 (43%)	237 (44%)
Jenin	36 (7%)	35 (7%)
Jericho	5 (1%)	5 (1%)
Jerusalem	13 (2%)	10 (2%)
Nablus	64 (12%)	54 (10%)
Qalqilyah	12 (2%)	12 (2%)
Ramallah	99 (19%)	54 (10%)
Salfit	6 (1%)	7 (1%)
Tulkarm	19 (4%)	9 (2%)
Beit Hanoun	1 (<1%)	0
Other places	0	69 (13%)

3.2 Consanguineous Marriage

Fifty three percent of parents were consanguineous, 61% of them with a first-degree blood relative. 20% were considered as a second-degree blood relative (Table 3.3).

Table 3.3

Consanguineous Marriage

Consanguinity status	Yes	281 (53%)
	No	251 (47%)
Blood relationship between parents	First degree	172 (61%)
	Second degree	57 (20%)
	More distant cousins	52 (19%)

3.3 Family Demographics:

Only 13% of cleft patients had a first-degree blood relationship with a cleft patient within their families, and 43% had other relatives with clefts, with rare genetic syndromes or Thalassemia in both the mother's and father's families (Table 3.4).

Table 3.4*Family Demographics*

Family Clefting blood relationship	First degree	68 (13%)
	Other relatives	232 (43%)
Genetic Syndromes	Mother family	39 (7%)
	Father family	42 (8%)
Thalassemia	Mother family	18 (3%)
	Father family	21 (4%)

3.4 The Relation between Parents' Age and Cleft Incidence:

Seventy three percent of mothers were between 21 to 35 years old at the time of conception (the average age for all participated mothers was 27.2 years old). Also, 67% of fathers were between 21 to 35 years old when their wives become pregnant; the average age for all participated fathers was 32.6 (Table 3.5).

Table 3.5*Parents' age*

Mothers' age at conception	<21	85 (16%)
	21-35	382 (73%)
	>35	59 (11%)
Fathers' age at conception	<21	10 (2%)
	21-35	347 (67%)
	>35	163 (11%)

3.5 Prenatal Care and Ultrasound Imaging:

Ninety five percent of patients' mothers received the prenatal care (on average, the first visit was at week 33.5 of pregnancy), 84% of mothers have received an ultrasound at least one time during pregnancy and only 14% of clefts appeared in that ultrasound (Table 3.6).

Table 3.6*Prenatal health*

Receiving Prenatal care	Yes	505 (95%)
	No	23 (4%)
Receiving Ultrasound	Yes	449 (84%)
	No	79 (15%)
Cleft appears in Ultrasound	Yes	63 (14%)
	No	377 (5%)

3.6 Using Folic Acid and Multivitamins Before and During Pregnancy

Before the upcoming pregnant, only 5% of mothers took FA, 2% took prenatal vitamins, 1% took calcium and 1% took iron. During pregnancy: 60% of mothers took FA, 44% prenatal vitamins, 49% took calcium and 71% took iron (Table 3.7).

Table 3.7

Folic Acid and multivitamins

Before pregnancy	Folic acid	26 (5%)
	Prenatal vitamins	10 (2%)
	Calcium	4 (1%)
	Iron	8 (1%)
During pregnancy	Folic acid	319 (60%)
	Prenatal vitamins	235 (44%)
	Calcium	260 (49%)
	Iron	378 (71%)

Smoking During Pregnancy:

Few mothers smoked during pregnancy (4% smoked either a cigarette or argyle), but 64% of mothers were exposed to second-hand smoke during pregnancy (84% of them were exposed daily (Table 3.8). Out of 344 of the mothers were living with smoking person during her pregnancy, 28% of these smokers were smoking inside the home, 9% were smoking outside the home and 62% were smoking both inside and outside the home (Figure 3.2).

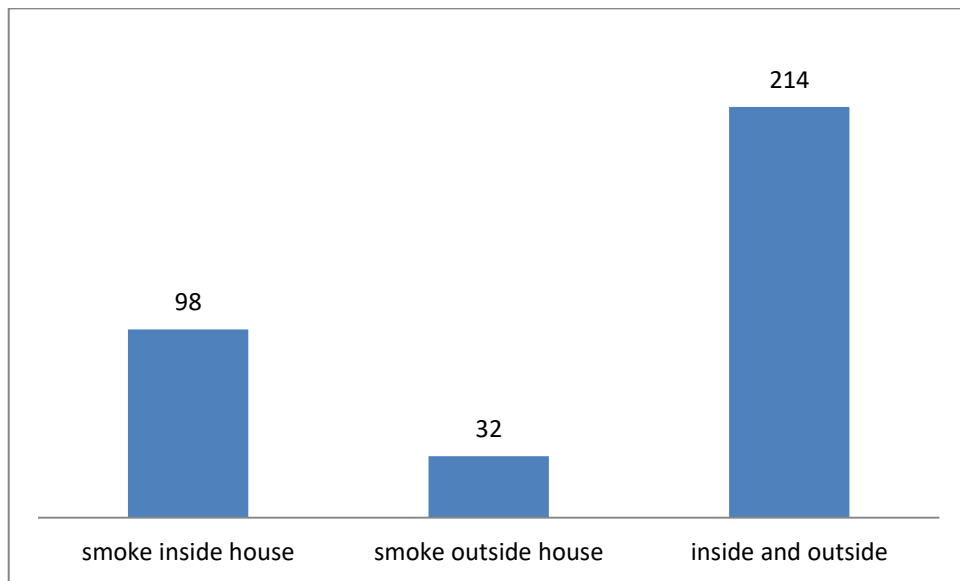
Table 3.8

Smoking

Maternal smoking	Yes	22 (4%)
	No	512 (96%)
Mother living with someone smoking	Yes	344 (64%)
	No	190 (36%)

Figure 3.2

Place of Exposing to Smoking



Chapter Four

Discussion

Worldwide, many studies have reported that there is no significant association between gender and oral clefts.(Natsume, Kawai et al. 2000) This is similar to this study results. Also, many studies have shown that there is an association between maternal age and having a cleft baby,(Baird, Sadovnick et al. 1994, Figueiredo, Ly et al. 2015) but in this study, 73% of mothers and 67% of fathers were between age 21-35, with an average 27.1 for mothers and 32.6 for fathers, so this is not appear to be as an association between maternal or paternal age and oral clefts. This result is like previous studies. (Jagomagi, Soots et al. 2010, Golalipour, Kaviany et al. 2012)

Another study reported that there was a relationship between refugee status and cleft incidence because of lack of social insurance which affects the treatment and cleft detection.(Kawalec, Nelke et al. 2015) But in this study there is no association between incidence of cleft and refugee status, because the refugees in this study are considered displaced people, were they expelled from their homes at 1948 and moved to other areas within Palestine. Also, there is no significant association between incidence of cleft and rural or urban status, small distances between rural and urban regions may be play a role (West Bank area is 5655 km² according to Palestinian Ministry of Local Government). Also, the distribution of the population between urban and rural areas, where the proportion of the rural population is 60.97% in the West Bank, while the urban is 32.03% and the percent of refugees is 7%. (Ghodieh 2005)

4.1 Prenatal Care

Most of the participated mothers in this study received prenatal care (95% of them), while 60% of mothers took FA during pregnancy. Only 5% took FA before pregnancy, which may have enhanced clefting rates.(van Rooij, Ocke et al. 2004, Wilcox, Lie et al. 2007)

4.2 Using Ultrasound for Early Cleft Detection

Several studies reported that CL can be detected at week 22 to 25 of pregnancy by axial 3-dimensional or 4-dimensional ultrasound.(Loozen, Maarse et al. 2015) 95% of mothers who received prenatal care, 84% of them were received ultrasound, only 14% of CL fetuses were detected by ultrasound; the other CL fetuses did not appeared because of using 2-dimensional ultrasound. Financial and travel constraints were the common reasons for not receiving prenatal care and not receiving 3D or 4D ultrasound, where 3D or 4D ultrasound devices are not available easily in all regions and clinics, and if they are available, the cost for 3D or 4D ultrasound is nearly four times the 2D ultrasound cost (60 USD for 3D or 4D, and 15 USD for 2D). Note that only 2D US is available in government healthcare clinics which are provided for free. However, most of pregnant women resort to private clinics to obtain additional health care due to the large number of government health care clinics visitors who receive prenatal care by midwives or nurses during most of their visits not by doctor.

4.3 Effect of Exposing to Smoking During Pregnancy

In this study, the smoking rate for patients' cleft's mothers was 4% and was 64% for mothers who exposed to second-hand smoking (most of them were exposed daily). This could be an indication of an association between smoking and incidence of clefts among Palestinians. Also there have been previous studies (Little, Cardy et al. 2004, Krapels, Zielhuis et al. 2006, Honein, Rasmussen et al. 2007) demonstrating a strong association between CL/P and second hand-smoking.(Dien, McKinney et al. 2018) 47.7% of Palestinian males are smokers, changing their smoking behavior will be required to decrease the rate of second-hand smoke exposure in the general population which will be lead to decrease the risk and incidence of clefts.(Abu Seir, Kharroubi et al. 2020)

4.4 The Relationship between Consanguineous Marriage and Clefting

The prevalence and incidence of OC in the Palestinian territories may be higher than in surrounding countries, due a high incidence of consanguineous marriages. Many studies showed an association between the consanguinity marriage and incidence of clefts. (Shafi, Khan et al. 2003, Bromiker, Glam-Baruch et al. 2004, Jamilian, Sarkarat et al. 2017)

In the Middle East, consanguinity rates are approximately 50%, which is significantly higher than other regions; this is because of cultural and religious factors.(Mehndiratta, Paul et al. 2007, Islam, Ababneh et al. 2018) A published paper in 2001 reported that 60% of Palestinian couples are first- and second-degree cousins, (A 2001) another paper indicates that the consanguinity rate for the previous generation is 45.2% and 39.9% for the current generation.(Sirdah 2014) This may indicate that the consanguinity rate is decreasing by generations among Palestinians. (Sirdah 2014, Islam, Ababneh et al. 2018) Another factors that may played a role in decreasing consanguinity rates in Palestine were improved the education rate among women, improved economic status and increased mobility between rural and urban regions.(Tadmouri, Nair et al. 2009) Also, using social media websites is raising the awareness of health care (Griffiths, Dobermann et al. 2015) and improving pregnancy care. (Hall, Fottrell et al. 2014) Using social media is popular in Palestine according to a report in 2019, where 92.2% were using Facebook, 72.3% were using Whatsapp, 61.8% were using Instagram, 60.7% were using YouTube and 25.6% were using Twitter. (2019) All of the previous points maybe the reasons of decreasing consanguineous marriage in Palestine.

The consanguinity rate in this study is 53%, 61% of them have a first-degree blood relative, which is higher than the consanguinity for the general population. A published research reported that consanguinity doubles the risk for non-syndromic clefts.(Ravichandran, Shoukri et al. 2012)

4.5 The Effect of COVID-19 on Cleft Care

With the spread of the COVID-19, quarantines, the closure of many facilities, the disruption of work and interruption of salaries for the employees, all these reasons have been contributed to the increase in the financial difficulties of Palestinian families, which may prevent some of them to visit private clinics due to cost, and reduce the number of follow up visits required during pregnancy, especially with the closure of health care clinics during the period of quarantine to prevent the outbreak of the COVID-19. Also, the presence of male smokers in their homes has increased due to the quarantine, which may increase the risk of having new babies with clefts because of the increased exposing to second-hand smoke.

As was mentioned previously, consanguineous marriages in Palestine have decreased during the last three generations due to increases in the education of women, improved economic status, increased mobility between rural and urban regions, and increased use of social media.(Tadmouri, Nair et al. 2009) All of these trends have been affected during the Pandemic because of quarantine. People could not move between cities and students were not able to go to schools or universities for months, which may reverse the rate of consanguineous marriage, leading to increases the consanguinity rate. At the same time, using of social media websites and Mobile applications have increased during quarantine; this could be a way to continue to decrease consanguineous marriage for this generation and for future generations. As was reported previously, social media raises the awareness of health care (Griffiths, Dobermann et al. 2015) and improves pregnancy health.(Hall, Fottrell et al. 2014)

4.6 Conclusion

The findings of this study suggest that gender, refugee status, or civil status are not significantly associated with an increased risk of CL/P. However, consanguinity was significantly associated with an increase in the rate of clefting and higher in the southern region than in other West Bank regions. Furthermore, maternal smoking or secondhand smoking and lack of FA intake before and during pregnancy period appeared to be possible risk factors for the birth of Palestinian children with clefts.

4.7 Recommendations

Further studies and awareness campaigns are required to clarify the importance of prenatal care and avoiding consanguineous marriage, especially in the southern regions. These strategies will help parents to decrease the chances of having children with clefts. This can be done using two different strategies:

- Education to increase awareness of the general population about the risk factors of clefts. The education programs should focus on the importance of taking FA before and during the first trimester of pregnancy and avoiding smoking or exposing to secondhand smoking during pregnancy.
- Education programs about OC should take in consideration the population age and educational differences, for example: educational activities for primary school students, and lectures for university students and high school students, and the relevant institutions should also perform their work in increasing the awareness of the community members about clefts.
- Genetic counseling should be provided for individuals and families, especially to consanguineous couples or families with a previous cleft history or for the parents of a cleft child to avoid having another child with a cleft. Genetic counseling is very important for consanguineous parents to avoid having children with clefts and other genetic diseases, and to give them more information about how genetic conditions might affect that family.
- Building a data base containing the Palestinian cleft patients' data.
- Further studies are needed regarding the incidence of CL/P, applying studies using a case-control study design, including other risk factors such as taking vitamin A, and study the effect of using sperm separation techniques on having cleft baby.

4.8 Limitations

Although the research has reached its goal of understanding the risk factors of clefting among Palestinians, there were some unavoidable limitations. One of the main limitations was that the sample did not include all Palestinians, as the study included only Palestinians who live in the territories of the Palestinian Authority in the West Bank and did not include other areas in the West Bank or residents of the Gaza Strip. Another limitation is not studying the effect of alcohol during pregnancy on cleft incidence, due to religious reasons and cultural taboos about alcohol in this region.

In addition, because of the limited studies, statistics, and data for Palestinian cleft patients, all these reasons led to a lack of a good understanding of cleft in Palestine or track the real number of newborns with clefts in each city. Also, the study does not identify the association between cleft patients who born with syndromes that may considered as the main cause of clefts, because of lack of a database or medical history including the diagnosis of cleft patients with one of these syndromes.

The last limitation is that the study including the patients who came to government hospitals for follow-up or to receive surgeries, and the other cleft patients were not included.

List of Abbreviations

Abbreviation	Meaning
CL/P	Cleft Lip with or without Cleft Palate
OA	Orofacial Anomaly
CLP	Cleft Lip with Cleft Palate
CL	Cleft Lip
CP	Cleft Palate
OC	Orofacial Cleft
FA	Folic Acid

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Appendices

Appendix A

Survey Palestinian National Congenital A

Confidential

Palestinian National Congenital Anomalies Study
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Demographics

Registry number

What type of encounter is this?

- ☐ Smile Train encounter form
☐ Follow-up (Contact info and healthcare update questions)
☐ Research survey (Full length survey)

Please enter the Smile Train number for this encounter.

Full name of the researcher who is administering the survey

Site of registry data entry

(City Name)

Date of screening

(YYYY-MM-DD)

Screening location

(Name of hospital or center)

Folder Number

Demographic Characteristics

Signed Smiletrain form

Please list all Smile Train form numbers available for this patient that have NOT been uploaded to Smile Train for reimbursement.

Please list all Smile Train form numbers available for this patient that have HAVE been uploaded to Smile Train for reimbursement.

Date patient signed consent

(YYYY-MM-DD)

Is the patient a minor (less than 18 years old)?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please upload minor consent form

Please upload adult consent form

Additional Form 1

Additional Form 2

Additional Form 3

Patient Identity Card Number

Placeholder Record?

- ☐ Yes
☐ No
(Answer Yes if record is for a relative of another patient in the database awaiting full survey.)

04/03/2018 4:09am

www.projectredcap.org



Is this a maternal interview?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

If no, select who is being interviewed

- ☐ Father
☐ Grandfather
☐ Grandmother
☐ Other
☐ Missing

If other, please explain

Does the patient have a birth defect?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

If yes, does this patient have a cleft?

- ☐ Yes
☐ No
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If yes, what type of cleft?

- ☐ Cleft lip only
☐ Cleft lip and palate
☐ Cleft palate only
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If no, indicate the patient's birth defect(s)

- ☐ Microtia
☐ Club foot
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

First Name

Middle Name

Family Name

Full name in Arabic

(type name in Arabic script)

Contact Information

Is the patient a refugee?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

If yes, does the patient live in a refugee camp?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Why do you consider yourself a refugee?

Has this patient ever received UNRWA services?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What type of UNRWA services has this patient received?

Street Address

City, Town, or Village

- ☐ Beit Jala
☐ Bethlehem
☐ Jenin
☐ Jericho
☐ Nablus
☐ Qalqilyah
☐ Ramallah
☐ Salfit
☐ Tulkarm
☐ Hebron
☐ Beit Hanoun
☐ Beit Lahia
☐ Deir el-Balah
☐ Gaza
☐ Jabalia
☐ Khan
☐ Yunis
☐ Rafah
☐ Tel Aviv
☐ Jerusalem
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Province

Country

Zip Code

Phone number

(Include Area Code)

Second phone number

(Include Area Code)

E-mail

Gender

- ☐ Female
☐ Male
☐ Don't know
☐ Choose not to answer
☐ Missing

Has the patient given birth before?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How many times has the patient given birth?

(("Don't know" = 999. "Choose not to answer" = 1000.)

Race

- ☐ Caucasian
☐ African
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

Please specify other race

Date of birth

(YYYY-MM-DD)

Patient's age at time of survey (years)

(Years old)

Patient's age at time of survey (months)

Patient's age today (years)

Patient's age today (months)

Height

(cm. "Don't know" = 999. "Choose not to answer" = 1000.)

Weight

(kg. "Don't know" = 999. "Choose not to answer" = 1000.)

BMI (Calculated)

(Calculated field to categorize height)

(1=short, 2=avg, 3=tall)

Parent/Guardian Information

First Name

Middle Name

Family Name

Relationship with patient

- ☐ Mother
- ☐ Father
- ☐ Grandparent
- ☐ Brother
- ☐ Sister
- ☐ Aunt
- ☐ Uncle
- ☐ Cousin
- ☐ Friend
- ☐ Self
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

How did the patient hear about The Smile Train?

- ☐ Charity Organization
- ☐ Hospital/physicians
- ☐ Newspaper and TV
- ☐ Internet
- ☐ Friends and relatives
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Patient's Mother Identification (ID) Number (if available)

Patient's Father Identification (ID) Number (if available)

Patient Birth History

Length of pregnancy

(Months. "Don't know" = 999. "Choose not to answer" = 1000.)

Patient birth weight

(kg. "Don't know" = 999. "Choose not to answer" = 1000.)

Type of birth

- ☐ Vaginal delivery
- ☐ C-section
- ☐ Induction of labor
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Were there any maternal complications during pregnancy?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If yes, what were the maternal complications during pregnancy?

Were there any fetal complications during pregnancy?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If yes, what were the fetal complications during pregnancy?

When the patient was born, were other children born by the same mother at the same time?

-
- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How many children were born at the time of delivery?

("Don't know" = 999. "Choose not to answer" = 1000.)

Were they identical?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Where was this patient born?

- ☐ Home
☐ Hospital
☐ Clinic
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Was there a health care provider present during the delivery of this patient?

-
- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all health care providers available

- ☐ Midwife
☐ Nurse
☐ Medical Doctor
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Were there any maternal complications during labor and delivery?

-
- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Indicate all maternal complications during labor and delivery

- ☐ Excess bleeding
☐ Difficulty delivering placenta
☐ Failure to progress
☐ Infection
☐ Eclampsia
☐ Seizures
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Were there any fetal complications during labor and delivery?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Indicate all fetal complications during labor and delivery

- ☐ Excess bleeding
☐ Change in baby's heart rate
☐ Umbilical cord ties
☐ Infection
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

How many days did the mother spend in the hospital? after delivery of this patient?

(Days. "Don't know" = 999. "Choose not to answer" = 1000.)

How many days did the patient spend in the hospital? immediately after birth?

(Days. "Don't know" = 999. "Choose not to answer" = 1000.)

Did the patient develop a complication(s) during his/her first week of life?

- ☐ Yes,
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all complications

- ☐ Difficulty feeding
☐ Abnormal weight loss
☐ Difficulty breathing
☐ Infection
☐ Failure to thrive
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Did the patient receive a newborn screening test(s) in his/her first week of life?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all known received screening tests

- ☐ PKU
☐ Sickle Cell
☐ Galactosemia
☐ Congenital hypothyroidism
☐ Cystic Fibrosis
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Did the Mother smoke during pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How often did the mother smoke while pregnant with this child?

- ☐ Every day
- ☐ Once a week
- ☐ Once a month
- ☐ Less than once a month
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Did the Mother consume alcohol during pregnancy with this patient?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

How often did the mother consume alcohol during her pregnancy with this patient?

- ☐ Every day
- ☐ Once a week
- ☐ Once a month
- ☐ Less than once a month
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

How many weeks pregnant was the mother while consuming alcohol?

(Weeks. "Don't know" = 999. "Choose not to answer" = 1000.)

Patient Family History

Do any of the patient's parents and/or siblings brothers/sisters have cleft lip, cleft palate, or cleft involving the face.

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

What is their relationship(s) with the patient?

- ☐ Brother
- ☐ Sister
- ☐ Twin
- ☐ Mother
- ☐ Father
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Do any other relatives (cousins, aunts, uncles, grandparents) have a cleft lip, cleft palate, or cleft involving the face.

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

What is their relationship(s) with the patient?

- ☐ Cousin
- ☐ Aunt
- ☐ Uncle
- ☐ Grandparent
- ☐ Son/daughter
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Household Historical Information

What city/village is the patient's family originally from?

- ☐ Beit Jala
☐ Bethlehem
☐ Jenin
☐ Jericho
☐ Nablus
☐ Qalqilyah
☐ Ramalla
☐ h Salfit
☐ Tulkarm
☐ Hebron
☐ Beit Hanoun
☐ Beit Lahia
☐ Deir el-Balah
☐ Gaza
☐ Jabalia
☐ Khan Yunis
☐ Rafah
☐ Tel Aviv
☐ Jerusalem
☐ Tubas
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Please list the dates and locations of other cities/villages you have lived, excluding your current and original addresses

Is the patient's current home in an urban or rural area?

- ☐ Urban
☐ Rural
☐ Don't know
☐ Choose not to answer
☐ Missing

How many people currently live in the patient's household?

("Don't know" = 999. "Choose not to answer" = 1000.)

Are three or more people sleeping in the same bedroom?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What was the approximate annual household income (in shekels) the year before this patient's birth?

(Enter "999" for unknown or choose not to answer.)

What is currently the approximate annual household income (in shekels)?

(Enter "999" for unknown or choose not to answer.)

Do other families living near the patient have children with cleft lip/palate?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How many families?

("Don't know" = 999. "Choose not to answer" = 1000.)

Are any of these families related to the patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Notes

What is the reason for this patient's visit?

Please list any changes since the patient's last visit, including intervening surgeries, changes in health, or anything else that affects the patient's overall well-being.

Additional comments

Diagnosis

Did the patient have any lip or palate surgery before this evaluation?

- ☐ Yes
☐ No
☐ Non-applicable
☐ Don't know
☐ Choose not to answer
☐ Missing

If yes, please indicate what type of surgery the patient had

- ☐ Cleft Lip Surgery
☐ Cleft Palate Surgery
☐ Cleft Lip and Palate Surgery
☐ Don't know
☐ Choose not to answer
☐ Missing

Does the patient have a cleft lip?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate what type of cleft lip

- ☐ Complete cleft lip on left side
☐ Complete cleft lip on right side
☐ Incomplete cleft lip on left side
☐ Incomplete cleft lip on right side
☐ Don't know
☐ Choose not to answer
☐ Missing

Does the patient have an alveolar cleft?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate what type of alveolar cleft

- ☐ Complete alveolar cleft on left side
☐ Complete alveolar cleft on right side
☐ Incomplete alveolar cleft on left side
☐ Incomplete alveolar cleft on right side
☐ Don't know
☐ Choose not to answer
☐ Missing

Does the patient have a hard palate cleft?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Z

Please indicate what type of hard palate cleft

- ☐ Complete cleft palate on left side
☐ Complete cleft palate on right side
☐ Incomplete cleft palate on left side
☐ Incomplete cleft palate on right side
☐ Don't know
☐ Choose not to answer
☐ Missing

Does the patient have a soft palate cleft?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate what type of soft palate cleft

- ☐ Complete cleft
- ☐ Incomplete cleft
- ☐ Submucous
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

In addition to the cleft, are there additional craniofacial deformities?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please describe the additional craniofacial deformities

Indicate all the patient's craniofacial deformities

- ☐ Cervical spine malformation
- ☐ Larynx malformation
- ☐ Parathyroid gland malformation
- ☐ Thyroid gland malformation
- ☐ Cryptophthalmos
- ☐ Congenital ptosis
- ☐ Congenital ectropion
- ☐ Congenital entropion
- ☐ Congenital malformation of eyelid NOS Absence and agenesis of lacrimal apparatus Congenital stenosis and stricture of lacrimal duct Congenital malformation of lacrimal apparatus NOS Cystic eyeball
- ☐ Other anophthalmos
- ☐ Microphthalmos
- ☐ Macrophthalmos
- ☐ Congenital cataract
- ☐ Congenital displaced lens
- ☐ Coloboma of lens
- ☐ Congenital aphakia
- ☐ Spherophakia
- ☐ Congenital lens malformation NOS
- ☐ Coloboma of iris
- ☐ Absence of iris
- ☐ Congenital iris malformation NOS
- ☐ Congenital corneal opacity
- ☐ Congenital corneal malformations NOS
- ☐ Blue sclera
- ☐ Congenital malformations of anterior segment of eye (rieger's anomaly)
- ☐ Congenital anterior segment of eye malformation NOS
- ☐ Congenital malformation of vitreous humour
- ☐ Congenital malformation of retina
- ☐ Congenital malformation of optic disc
- ☐ Congenital malformation of choroid
- ☐ Congenital posterior segment of eye malformation NOS
- ☐ Congenital glaucoma
- ☐ Congenital eye malformation NOS
- ☐ Congenital absence of (ear) auricle
- ☐ Congenital absence, atresia and stricture of auditory canal (external)
- ☐ Absence of eustachian tube
- ☐ Congenital malformation of ear ossicles
- ☐ Congenital middle ear malformation NOS
- ☐ Congenital inner ear malformation NOS
- ☐ Congenital malformation of ear causing impairment of hearing NOS
- ☐ Accessory auricle
- ☐ Macrota
- ☐ Microta
- ☐ Another misshapen ear
- ☐ Misplaced ear
- ☐ Prominent ear
- ☐ Congenital malformation of ear NOS
- ☐ Sinus, fistula, and cyst of branchial cleft
- ☐ Preauricular sinus and cyst
- ☐ Other branchial cleft malformations
- ☐ Webbing of neck
- ☐ Macrostomia
- ☐ Microstomia
- ☐ Macrocheilia
- ☐ Microcheilia
- ☐ Other congenital malformation of face and neck
- ☐ Congenital malformation of face and neck unspecified
- ☐ Other
- ☐ Non-applicable
- ☐ Don't know
- ☐ Choose not to answer

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If other, please explain

Does this patient have velopharyngeal insufficiency
(Air escapes from nose while speaking) following
prior cleft palate repair?

Does this patient have abnormalities in his/her heart?

Does this patient have a heart and/or blood vessels
(Cardiovascular system) abnormality?

Please indicate all cardiovascular abnormalities

☐ Missing

- ☐ Yes?
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

- ☐ Anatomical defect since birth Acute
☐ myocardial infarction
☐ Atherosclerosis/peripheral vascular disease
☐ Irregular heart rhythm
☐ Stroke
☐ High blood pressure
☐ Low blood pressure
☐ Haemorrhoids
☐ Heart valve disease
☐ Cancer in heart or vessels
☐ Paroxysmal tachycardia
☐ Prominent veins
☐ Pulmonary hypertension
☐ Swollen ankles/edema
☐ Chest pain not otherwise specified
☐ Angina
☐ Atrial fibrillation/flutter
☐ Heart failure
☐ Heart/arterial murmur
☐ Infection of circulatory system
☐ Heart disease
☐ Varicose veins of leg
☐ Palpitations/awareness of heart
☐ Phlebitis/thrombophlebitis
☐ Pressure/tightness of heart
☐ Pulmonary embolism
☐ Rheumatic fever/heart disease
☐ Transient cerebral ischemia
☐ Limited function/physical disability caused by
disease in heart or vessels.
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Does this patient have a nose abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Does this patient have a fingers and toes abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Does this patient have a urinary system abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all urinary abnormalities

- ☐ Congenital (since birth) anomaly of urinary tract
☐ Bladder symptom/complaint
☐ Urinary disease
☐ Cystitis, urinary infection
☐ Glomerulonephritis/nephrosis
☐ Incontinence of urine (accidental loss of urine)
☐ Kidney symptom/complaint
☐ Benign cancer of bladder
☐ Kidney infection
☐ Infection of urethra
☐ Urinary symptom/complaint
☐ Benign cancer of urinary tract
☐ Malignant cancer of urinary tract
☐ Abnormal urine test
☐ Dysuria/painful urination
☐ Blood in urine
☐ Injury to urinary tract
☐ Urination problems
☐ Malignant cancer of bladder
☐ Protein in urine
☐ Urinary retention (unable to urinate easily)
☐ Limited function/disability caused by a urological condition
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Does this patient have an ear abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all ear abnormalities

- ☐ Congenital (since birth) anomaly of ear
- ☐ Bleeding ear
- ☐ Ear disease
- ☐ Deafness
- ☐ Acoustic Trauma
- ☐ Ear Injury
- ☐ Eustachian tube dysfunction
- ☐ Foreign body in ear
- ☐ Cancer of ear
- ☐ External ear infection
- ☐ Perforation of ear drum
- ☐ Presbycusis
- ☐ Superficial injury of ear
- ☐ Acute ear infection
- ☐ Chronic ear infection
- ☐ Ear discharge
- ☐ Ear pain/earache
- ☐ Excessive ear wax
- ☐ Hearing complaint
- ☐ Vertigo
- ☐ Otosclerosis
- ☐ Plugged feeling in ear
- ☐ Serous otitis media
- ☐ Ringing/buzzing in ear
- ☐ Limited function/physical disability caused by ear condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a skin abnormality?

-
- ☐ Yes
 - ☐ No
 - ☐ Don't know
 - ☐ Choose not to answer
 - ☐ Missing

Please indicate all skin abnormalities

- ☐ Congenital (since birth) skin anomaly
- ☐ Animal/human bite
- ☐ Burns
- ☐ Skin cancer
- ☐ Abrasion/scratch/blister
- ☐ Dermatitis contact/allergic
- ☐ Dermatitis/atopic eczema
- ☐ Diaper rash
- ☐ Hemangioma/lymphangioma
- ☐ Hair/scalp symptom, complaint
- ☐ Herpes zoster
- ☐ Infected finger/toe
- ☐ Laceration/cut
- ☐ Lipoma
- ☐ Lumps/swelling generalized
- ☐ Lumps/swelling localized
- ☐ Candidiasis of skin
- ☐ Nail symptom/complaint
- ☐ Pediculosis/skin infestation
- ☐ Pityriasis rosea
- ☐ Psoriasis
- ☐ Rash localized
- ☐ Sebaceous cyst
- ☐ Skin infection
- ☐ Skin injury
- ☐ Solar Keratosis, sunburn
- ☐ Urticaria
- ☐ Acne
- ☐ Insect bite
- ☐ Bruise
- ☐ Chronic ulcer
- ☐ Skin disease
- ☐ Corn/callous
- ☐ Dermatitis seborrheic
- ☐ Dermatophytosis
- ☐ Foreign body in skin
- ☐ Hair loss/baldness
- ☐ Herpes simplex
- ☐ Impetigo
- ☐ In growing nail
- ☐ Alopecia
- ☐ Benign cancer of skin
- ☐ Malignant cancer of skin
- ☐ Mole
- ☐ Pain/tenderness in skin
- ☐ Pilonidal cyst/fistula
- ☐ Pruritis
- ☐ Rash generalized
- ☐ Scabies
- ☐ Skin color change
- ☐ Skin infection, post-traumatic
- ☐ Skin texture complaint
- ☐ Sweat gland disease
- ☐ Warts
- ☐ Limited function/physical disability caused by skin condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have an eye abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all eye abnormalities

- ☐ Congenital (since birth) eye anomaly (i.e. coloboma)
☐ Blepharitis/stye/chalazion
☐ Blocked lacrimal duct as infant
☐ Eye disease
☐ Conjunctivitis
☐ Eye trauma
☐ Detached retina
☐ Eye movement abnormal
☐ Eye sensation abnormal
☐ foreign body in eye
☐ Macular degeneration
☐ Red eye
☐ Retinopathy
☐ Visual disturbance
☐ Acute vision changes
☐ Blindness
☐ Cataracts
☐ Conjunctivitis infectious
☐ Corneal ulcer
☐ Eye appears abnormal
☐ Eye inflammation
☐ Eye pain
☐ Eyelid symptom
☐ Glaucoma
☐ Exotropia/Esotropia
☐ Refractory eye disease
☐ Strabismus
☐ Visual floaters/spots
☐ Limited function/physical disability caused by eye condition
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Does this patient have a limb (arms/legs) abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Does this patient have a tongue abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Does this patient have a skull abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Does this patient have a mandible abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Does this patient have retarded growth?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Does this patient have mental retardation?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Does this patient have a speech abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all speech abnormalities

- ☐ Receptive language delays, (i.e., difficulty understanding others)
☐ Expressive language delays, (i.e., difficulty communicating with others)
☐ Poor clarity of speech, (i.e., pronounces words incorrectly)
☐ Unusual resonance, (i.e. voice sounds too nasal, air is audible through nose during speech or patient's nose always sounds blocked up during speech)
☐ Voice sounds raspy or hoarse
☐ Patient stammers/stutters
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Did any of these issues begin after trauma, illness or surgery?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain

Have any of these speech abnormalities resolved?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain how these speech abnormalities have resolved

Does this patient have a blood and/or immune system abnormality?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all blood and immune abnormalities

- ☐ Congenital (since birth) anomaly blood/lymph
- ☐ Anemia other/unspecified
- ☐ Anemia vitamin B12/folate deficiency
- ☐ Blood symptom/complaint
- ☐ Blood/lymph/spleen disease
- ☐ Concern about AIDS/HIV
- ☐ Concern about cancer blood/lymph
- ☐ Hodgkin's disease/lymphoma
- ☐ Leukemia
- ☐ Unexplained abnormal white cells
- ☐ Lymph gland(s) enlarged/painful
- ☐ Lymph immune mechanism symptom
- ☐ Lymphadenitis acute
- ☐ Lymphadenitis chronic
- ☐ Benign cancer blood
- ☐ Malignant cancer blood
- ☐ Purpura/coagulation defect
- ☐ Ruptured spleen traumatic
- ☐ Splenomegaly (large spleen)
- ☐ Limited function/physical disability caused by blood and immune condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a digestive tract abnormality?

-
- ☐ Yes
 - ☐ No
 - ☐ Don't know
 - ☐ Choose not to answer
 - ☐ Missing

Please indicate all digestive tract abnormalities

- ☐ Congenital (since birth) anomaly of digestive system
- ☐ Epigastric abdominal pain
- ☐ Localized abdominal pain
- ☐ General abdominal pain/cramps
- ☐ Anal fissure/perianal abscess
- ☐ Appendicitis
- ☐ Abnormal bowel movements
- ☐ Gallbladder infection
- ☐ Gallstones
- ☐ Chronic enteritis
- ☐ Ulcerative colitis
- ☐ Crohn's disease
- ☐ Constipation
- ☐ Diarrhea
- ☐ Diverticular Disease
- ☐ Duodenal ulcer
- ☐ Dyspepsia/indigestion
- ☐ Excess flatulence/gas/belching
- ☐ Stomach infection
- ☐ Foreign body in digestive system
- ☐ Digestive tract infection
- ☐ Vomiting blood
- ☐ Heartburn
- ☐ Enlarged liver
- ☐ Hiatus hernia
- ☐ Incontinence (loss of control) of bowel
- ☐ Injury to digestive tract
- ☐ Esophageal disease
- ☐ Peptic ulcer disease
- ☐ Perianal itching
- ☐ Rectal bleeding
- ☐ Rectal/anal pain
- ☐ Stomach function disorders
- ☐ Swallowing problem
- ☐ Teeth/gum disease
- ☐ Viral hepatitis
- ☐ Vomiting
- ☐ Limited function/physical disability caused by digestive tract condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have an endocrine (hormonal) system/metabolic system/nutrition abnormality?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please indicate all abnormalities in endocrine (hormonal) system/metabolic system/nutrition

- ☐ Congenital (since birth) problem
- ☐ Benign cancer of thyroid
- ☐ Malignant cancer of thyroid
- ☐ Endocrine system cancer
- ☐ Endocrine/metabolic disease
- ☐ Dehydration
- ☐ Diabetes insulin dependent
- ☐ Diabetes non-insulin dependent
- ☐ Diabetic Ketoacidosis
- ☐ Excessive appetite
- ☐ Goiter
- ☐ Growth delay
- ☐ Hypoglycemia
- ☐ Lipid disorder
- ☐ Loss of appetite
- ☐ Obesity
- ☐ Thyroglossal duct/cyst
- ☐ Rapid weight gain
- ☐ Rapid weight loss
- ☐ Excessive thirst
- ☐ Gout
- ☐ Hyperthyroid/thyrotoxicosis
- ☐ Hypothyroid
- ☐ Endocrine infection
- ☐ Overweight
- ☐ Underweight
- ☐ Vitamin/nutritional deficiency
- ☐ Limited function/physical disability caused by endocrine (hormonal) system/metabolic system/nutrition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a female genital abnormality?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please indicate all female genital abnormalities

- ☐ Congenital (since birth) anomaly of genitals
- ☐ Abnormal cervix smear
- ☐ Benign cancer genital
- ☐ Malignant cancer genital
- ☐ Benign cancer breast
- ☐ Malignant cancer breast
- ☐ Breast lump/mass
- ☐ Breast pain
- ☐ Cervical disease
- ☐ Chlamydia
- ☐ Abnormal breast appearance
- ☐ Genital cancer
- ☐ Sexual dysfunction
- ☐ Sexually transmitted disease
- ☐ Condylomata acuminata
- ☐ Fibrocystic breast disease
- ☐ Uterine fibroids
- ☐ Genital candidiasis
- ☐ Genital disease
- ☐ Genital herpes
- ☐ Genital pain
- ☐ Genital trichomoniasis
- ☐ Gonorrhea
- ☐ Injury genital
- ☐ Intermenstrual bleeding
- ☐ Intermenstrual pain
- ☐ Menstrual pain
- ☐ Vulval symptom/complaint
- ☐ Menstruation absent/scanty
- ☐ Menstruation irregular/frequent
- ☐ Painful intercourse
- ☐ Pelvis symptom/complaint
- ☐ Syphilis
- ☐ Vaginal discharge
- ☐ Menstruation excessive
- ☐ Nipple symptom
- ☐ Pelvic inflammatory disease
- ☐ Bleeding after intercourse
- ☐ Uterovaginal prolapsed
- ☐ Vaginitis
- ☐ Limited function/physical disability caused by female genital condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a pregnancy/childbearing abnormality?

-
- ☐ Yes
 - ☐ No
 - ☐ Don't know
 - ☐ Choose not to answer
 - ☐ Missing

Please indicate all abnormalities with pregnancy
childbearing

- ☐ Abortion induced and/or
- ☐ Abortion spontaneous
- ☐ Bleeding during pregnancy Breast
- ☐ disorder in pregnancy Complicated
- ☐ labor/delivery livebirth Complicated
- ☐ labor/delivery stillbirth Concern
- ☐ about body injury
- ☐ Ectopic pregnancy
- ☐ Gestational diabetes
- ☐ Infertility/sub-
- ☐ fertility
- ☐ Injury complicating pregnancy
- ☐ Lactation symptom/complaint
- ☐ Benign cancer in pregnancy
- ☐ Malignant cancer in pregnancy
- ☐ Other infection complicating pregnancy
- ☐ Post-pregnancy bleeding
- ☐ High risk pregnancy
- ☐ Pregnancy symptom/complaint
- ☐ Pregnancy
- ☐ Pregnancy vomiting/nausea
- ☐ Breast infection from breastfeeding
- ☐ Unwanted pregnancy
- ☐ Uncomplicated labor/delivery livebirth
- ☐ Uncomplicated labor/delivery stillbirth
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a male genital abnormality?

-
- ☐ Yes
 - ☐ No
 - ☐ Don't know
 - ☐ Choose not to answer
 - ☐ Missing

Please indicate all male genital abnormalities

- ☐ Congenital (since birth) anomaly of genital area
- ☐ Hydrocele
- ☐ Hypospadias
- ☐ Impotence
- ☐ Infertility
- ☐ Injury to genitals
- ☐ Gonorrhea
- ☐ Benign genital cancer
- ☐ Malignant genital cancer
- ☐ Testicular infection
- ☐ Infection to epididymis
- ☐ Pain in testis/scrotum
- ☐ Pain in penis
- ☐ Prostate symptom
- ☐ Inflammation of prostate
- ☐ Sterilization
- ☐ Syphilis
- ☐ Undescended testes
- ☐ Urethral discharge
- ☐ Genital disease
- ☐ Sexual dysfunction
- ☐ Sexually transmitted disease
- ☐ Condylomata acuminata
- ☐ Genital herpes
- ☐ Limited function/physical disability caused by male genital problem
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a neurological (brain, spinal cord, nerves) system abnormality?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please indicate all abnormalities in the neurological
(Brain, spinal cord, nerves) system

- ☐ Congenital (since birth) problem with nervous system (brain, spinal cord, nerves)
- ☐ Abnormal involuntary movements
- ☐ Benign cancer of nervous system
- ☐ Malignant cancer of nervous system
- ☐ Altered mental status
- ☐ Carpal tunnel syndrome
- ☐ Cluster headache
- ☐ Neurological disease
- ☐ Concussion
- ☐ Convulsion/seizure
- ☐ Disturbance of smell/taste
- ☐ Epilepsy
- ☐ Facial paralysis/bell's palsy
- ☐ Head injury
- ☐ Headache
- ☐ Injury to nervous system
- ☐ Meningitis/encephalitis
- ☐ Tourette's syndrome
- ☐ Migraine
- ☐ Multiple sclerosis
- ☐ Neurological infection
- ☐ Pain face
- ☐ Paralysis, weakness
- ☐ Parkinsonism
- ☐ Peripheral neuritis/neuropathy
- ☐ Radiculopathy
- ☐ Restless leg
- ☐ Sensation disturbance
- ☐ Speech disturbance
- ☐ Tension headache
- ☐ Tetanus
- ☐ Tingling fingers/feet/toes
- ☐ Tremor
- ☐ Trigeminal neuralgia
- ☐ Vertigo/dizziness
- ☐ Stammering/stuttering/tic
- ☐ Apraxia (limb/speech) "unable to follow commands"
- ☐ Stroke
- ☐ Mental Retardation
- ☐ Limited function/physical disability caused by neurological condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a psychological abnormality?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please indicate all psychological abnormalities

- ☐ Child behavior problem
- ☐ Adolescent behavior problem
- ☐ anxiety disorder/anxiety state
- ☐ Anorexia nervosa/bulimia
- ☐ Bedwetting/enuresis
- ☐ Bipolar disorder
- ☐ Delirium
- ☐ Depressive disorder
- ☐ Eating problem in child
- ☐ Feeling anxious/nervous/tense
- ☐ Feeling hypomanic
- ☐ Feeling/behaving irritable/angry
- ☐ Medication abuse
- ☐ Mental retardation
- ☐ Overworked, mental strain
- ☐ Phase of life problem
- ☐ Post-traumatic stress disorder
- ☐ Schizophrenia
- ☐ Sexual fulfillment reduced
- ☐ Sleep disturbance
- ☐ Specific learning problem
- ☐ Suicide attempt
- ☐ Chronic alcohol abuse
- ☐ Acute alcohol abuse
- ☐ Dementia
- ☐ Drug abuse
- ☐ Bowel training problem
- ☐ Feeling depressed
- ☐ Feeling manic
- ☐ Hyperactivity
- ☐ Autism
- ☐ Memory disturbance
- ☐ Personality disorder
- ☐ Phobia, compulsive disorder
- ☐ Psychological disorder
- ☐ Sexual preference concern
- ☐ Sexual desire reduced
- ☐ Somatization disorder
- ☐ Acute stress reaction
- ☐ Tobacco abuse
- ☐ Behavior disorder
- ☐ Limited function/physical disability caused by mental condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a respiratory system abnormality?

-
- ☐ Yes
 - ☐ No
 - ☐ Don't know
 - ☐ Choose not to answer
 - ☐ Missing

Please indicate all respiratory abnormalities

- ☐ Congenital (since birth) problem with respiratory system
- ☐ Breathing problem
- ☐ Asthma
- ☐ Allergic rhinitis
- ☐ Benign respiratory cancer
- ☐ Malignant respiratory cancer
- ☐ Acute bronchitis/bronchiolitis
- ☐ Chronic Obstructive pulmonary disease
- ☐ Lung cancer
- ☐ Lung disease
- ☐ Foreign body in respiratory system
- ☐ Cough up blood
- ☐ Hyperventilation
- ☐ Influenza
- ☐ Inflammation of larynx or trachea
- ☐ Nosebleed
- ☐ Pain in respiratory system
- ☐ Pleurisy
- ☐ Pneumonia
- ☐ Shortness of breath
- ☐ Strep throat
- ☐ Sneezing, nasal congestion
- ☐ Acute tonsil infection
- ☐ Acute pharyngitis without exudates
- ☐ Acute pharyngitis with exudates
- ☐ Boil/abscess nose
- ☐ Chronic bronchitis
- ☐ Respiratory system cancer
- ☐ Respiratory disease
- ☐ Cough
- ☐ Enlarged tonsils/adenoids
- ☐ Hypoventilation
- ☐ Injury to respiratory system
- ☐ Sleep Apnea
- ☐ Nose system, complaint
- ☐ Peritonsillar abscess
- ☐ Pleural effusion
- ☐ Respiratory infection
- ☐ Sinus symptom, complaint
- ☐ Sputum abnormal
- ☐ Throat symptom, complaint
- ☐ Voice symptom, complaint
- ☐ Limited function/physical disability caused by respiratory condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Does this patient have a musculoskeletal (MSK; bones and muscles) system abnormality?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please indicate all MSK abnormalities

- ☐ Congenital (since birth) problem in MSK system
- ☐ Deformity of limb
- ☐ Deformity of spine
- ☐ Internal knee damage
- ☐ Arm complaint
- ☐ Back complaint
- ☐ Back complaint with radiating pain
- ☐ Bursitis/tendinitis/synovitis
- ☐ Cancer in MSK system
- ☐ Dislocation/subluxation
- ☐ Flank/underarm complaint
- ☐ Femur fracture
- ☐ Fracture, other
- ☐ Tibia/fibula fracture
- ☐ Hip system
- ☐ MSK injury
- ☐ Joint symptom, complaint
- ☐ Leg, thigh symptom, complaint
- ☐ Low back symptom, complaint
- ☐ Neck symptom, complaint
- ☐ Benign MSK cancer
- ☐ Malignant MSK cancer
- ☐ Osteoarthritis of knee
- ☐ Osteoporosis
- ☐ Elbow symptom
- ☐ Foot/toe complaint
- ☐ Hand/foot bone fracture
- ☐ Radius, ulna fracture
- ☐ Hand/finger complaint
- ☐ Infection of MSK system
- ☐ Jaw symptom, complaint
- ☐ Knee symptom, complaint
- ☐ Myasthenia gravis
- ☐ Muscle pain
- ☐ Osteoarthritis of hip
- ☐ Osteochondrosis
- ☐ Rheumatoid arthritis
- ☐ Shoulder symptom, complaint
- ☐ Sprain/strain of joint
- ☐ Sprain/strain of ankle
- ☐ Tennis elbow
- ☐ Wrist symptom, complaint
- ☐ Limited function/physical disability caused by MSK condition
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Has this patient been diagnosed with a syndrome?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please describe the syndrome

Please indicate all environmental issues that affect
(Or have affected) the patient

- ☐ The water at home is not clean, it has many impurities
- ☐ The patient does not have access to neighborhood parks
- ☐ The house does not have central heating
- ☐ There is excessive crowding in the city/village in which the patient lives
- ☐ There is excessive noise in city/village in which the patient lives
- ☐ The air at home is not clean, it has many impurities
- ☐ The house does not have central air-conditioning
- ☐ The house is too small for the family size, and as a result is crowded
- ☐ The school is overcrowded
- ☐ The family does not own a car
- ☐ The patient encounters a checkpoint when traveling at least once a week
- ☐ None of the above
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Please indicate all social issues that affect (or have affected) the patient

- ☐ The patient does not listen to authority
- ☐ The patient is unable to obtain an education
- ☐ Food is not always available at home when the patient is hungry
- ☐ The patient has difficulty accessing healthcare
- ☐ The patient has (or had) an ill family member
- ☐ The patient has a legal problem, a problem with the government or law
- ☐ The patient has lost a child, or his/her child has died
- ☐ The patient has lost a sibling, or his/her sibling has died
- ☐ The patient has lost a family member, or his/her family member has died
- ☐ The patient has lost a close friend, or his/her close friend has died
- ☐ The patient is living in poverty
- ☐ The main provider(s) in the patient's home are unemployed
- ☐ The patient has difficulty communicating with others
- ☐ The patient experiences (or has experienced) teasing
- ☐ The patient does not have access to a safe school
- ☐ The patient has a learning problem
- ☐ The patient has seen or experienced domestic violence
- ☐ The patient has moved to a new home more than once in past year
- ☐ The patient has been physically assaulted
- ☐ The patient has observed violence outside the home
- ☐ Limited function/physical disability caused by social problem
- ☐ None of the above
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Notes

Please note any additional diagnoses or health concerns for this patient that are not mentioned above.

Additional comments

Development

Age of patient

Is your child 4 months old?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Is your child 6 months old?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Is your child 12 months (1 year) old?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Is your child 18 months (1.5 years) old?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Is your child 24 months (2 years) old?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Is your child 30 months (2.5 years) old?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Is your child 36 months (3 years) old?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Communication

Does your baby chuckle softly?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After you have been out of sight, does your baby smile or get excited when he sees you?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby stop crying when she hears a voice other than yours?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby make high-pitched squeals?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your baby laugh?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your baby make sounds when looking at toys or people?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Communication Total	<hr/> (Cut off 34.60)
Does your baby make high-pitched squeals?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
When playing with sounds, does your baby make grunting, growling, or other deep-toned sounds?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
If you call your baby when you are out of sight, does she look in the direction of your voice.	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
When a loud noise occurs does your baby turn to see where the sound came from?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your baby make sounds like "da," "ka," and "ba"?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
If you copy the sounds your baby makes, does your baby repeat the sounds back to you?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Communication Total	<hr/> (Cut off 29.0)
If you ask her to, does your baby play at least one nursery game even if you don't show her the activity yourself (e.g., "bye-bye," "clap your hands," "peekaboo")?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your baby follow one simple command, such as "Come here," "Give it to me," or "Put it back," without your using gestures.	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your baby say one word in addition to "Mama" and "Baba"? (A "word" is a sound or sounds that baby says consistently to mean someone or something.)	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
When you ask, "Where is the ball (hat, shoe, etc.)?" does your baby look at the object Make sure the object is present. Check "yes" if he knows one object.	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
When your baby wants something, does she tell you by pointing to it?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your baby shake his head when he means "no" or "yes"?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)

Communication Total

(Cut off 15.8)

When your child wants something, does she tell you by pointing to it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

When you ask him to, does your child go into another room to find a familiar toy or object. (You might ask, "Where is your ball" or say, "bring me your coat.")

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child say eight or more words in addition to "Mama" and "Baba"?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child imitate a two-word sentence? For example, when you say a two-word phrase, such as "Mama eat," "Come here," does your child say both back to you? (Check "yes" even if her words are difficult to understand.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0) words

Without showing him first, does your child point to the correct picture when you say, "Show me the cat" or ask, "Where is the dog?" (He needs to identify only one picture correctly.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child say two or three words that represent different ideas together, such as "see dog?" (don't count word combinations that express one idea, such as "bye bye," "all gone.")

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Communication Total

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)
 (Cut off 23.0)

Without showing her first, does your child point to the correct picture when you say, "Show me the cat" or ask, "Where is the dog?" (She needs to identify only one picture correctly.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child imitate a two-word sentence? For example, when you say a two-word phrase, such as "Mama eat," does your child say both words back to you? (Check "yes" even if his words are difficult to understand.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Without giving her clues by pointing or using gestures, can your child carry out at least three of these kinds of directions? (a) "Put the toy on the table." (b) "Close the door." (c) "Bring me a towel." (d) "Find your coat." (e) "Take my hand." (f) "Get your book."

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

If you point to a picture of a ball (cat, cup, hat, etc.) and ask your child, "What is this?" does your child correctly name at least one picture.

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child say two or three words that represent different ideas together, such as "See dog" (don't count words combinations that express one idea, such as "bye-bye")

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child correctly use at least two words like "Me," "I," "mine," and "you"?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Communication Total

If you point to a picture of a ball (hat, cup, etc) and ask your child, "What is this?" does your child correctly name at least one picture.

(Cut off

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Without giving him clues by pointing or using gestures, can your child carry out at least three of these kids of directions? (a) "Put the toy on the table." (b) "Close the door." (c) Bring me a towel." (d) "Find your coat." (e) "Take my hand." (f) "Get your book."

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you ask her to point to her nose, eyes, hair feet, ears, and so forth, does your child correctly point to at least seven body parts?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child make sentences that are three or four words long?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Is your child able to carry out these directions? "Put the shoe on the table" and "Put the book under the chair."

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When looking at a picture book, does your child tell you what is happening or what action is taking place in the picture? (For example, "running," "eating")

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Communication Total

(Cut off 38.8)

When you ask her to point to her nose, eyes, feet, and so forth, does your child correctly point to at least seven body parts?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child make sentences that are three or four words long?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Without giving him help by pointing or using gestures, if you asked your child to put a book under the table. Does he carry it out correctly?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When looking at a picture book, does your child tell you what is happening or what action is taking place in the picture? (For example, "crying," "running")

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

If you asked your child to push a zipper up and then down, and alternate (or a similar activity involving up and downs) does she consistently do it correctly?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you ask, "What is your name?" does your child say both her first and last names?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Communication Total

(Cut off 38.7)

Gross Motor

While on her back does your baby move her head from side to side?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After holding her head up while on her tummy, does your baby lay her head back down on the floor, rather than let it drop or fall forward?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When she is on her tummy does your baby hold her head up so that her chin is about 3 inches from the floor for at least 15 seconds?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When she is on her tummy does your baby hold her head straight up, looking around? (She can rest on her arms while doing this)

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you hold her in a sitting position does your babies hold her head steady.

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

While on her back, does your baby bring her hands together over her chest, touching her/his fingers?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Gross Motor Total

(cut off 38.41)

While on her/his back, does your baby lift his legs high enough to see her/his feet?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When she is on her tummy, does your baby straighten both arms and push her whole chest of the bed or floor?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby roll from his back to his tummy? getting both arms out from under him?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you put her on the floor, does your baby lean on her hands while sitting? (If she already sits up straight without leaning on her hands, check "yes" for this item.)

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

If you hold both hands just to balance him, does your baby support his own weight while standing?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby get into a crawling position by getting up on her hands and knees?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Gross Motor Total

(Cut off 19.5)

When holding onto furniture, does your baby bend down and pick up a toy from the floor and then return to a standing position?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

While holding onto furniture, does your baby lower herself with control (without falling or flopping down)?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby walk along furniture while holding on with only one hand?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
If you hold both hands just to balance him, does your babies take several steps without tripping or falling? (If your baby already walks alone, check "yes" for this item.)	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
When you hold one hand just to balance her, does your baby take several steps forward? (If your baby already walks alone, check "yes" for this item.)	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your baby stand up in the middle of the floor by himself and take several steps forward?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Gross Motor Total	<hr/> (Cut off 18.0)
Does your child bend over or squat to pick up an object from the floor and then stand up again without any support?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your child move around by walking, rather than by crawling on her hands and knees.	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your child walk well and seldom fall?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your child climb on an object such as a chair to reach something he wants?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your child walk down stairs if you hold onto one of her hands?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
When you show him how to kick a large ball, does your child try to kick the ball by moving his leg forward or by walking into it? (If your child already kicks a ball, check "yes" for this item.)	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Gross Motor Total	<hr/> (Cut off 41.5)
Does your child walk down stairs if you hold onto one of his hands?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
When you show her how to kick a large ball, does your children try to kick the ball, does your child try to kick the ball by moving her leg forward or by walking into it? (If your child already kicks a ball, check "yes" for this item.)	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your child walk either up or down at least two steps by himself? (Check "yes" even if he holds onto the wall or railing.)	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)
Does your child run fairly well, stopping herself without bumping into things or falling?	<input type="radio"/> Yes (10) <input type="radio"/> Sometimes (5) <input type="radio"/> Notyet (0)

Does your child jump with both feet leaving the floor at the same time?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Without holding onto anything for support, does your child kick a ball by swinging his leg forward.

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Gross Motor Total

(Cut off 36.0)

Does your child run fairly well, stopping herself without bumping into things or falling?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child walk up or down at least two steps by himself?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Without holding onto anything for support, does your child kick a ball by swinging his leg forward.

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child jump with both feet leaving the floor at the same time?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child walk up stairs, using only one foot on each stair? (He may use the rail.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child stand on one foot for about 1 second without holding onto anything.

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Gross Motor Total

(Cut off 30.6)

Without holding onto anything for support, does your child kick a ball by swinging his leg forward.

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child jump with both feet leaving the floor at the same time?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child walk up stairs, using only one foot on each stair? (may hold onto a rail)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child stand on one foot for about 1 second without holding onto anything.

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

While standing, does your child throw a ball overhand by raising his arm to shoulder height and throwing the ball forward?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child jump forward at least 6 inches with both feet leaving the ground at the same time?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Gross Motor Total

(Cut off 35.7)

Fine Motor

Does your baby hold his hands open or partly open (rather than in fists, as they were when he was a newborn)?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you put a toy in her hand, does your baby wave it about at least briefly?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby grab or scratch at his clothes?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you put a toy in her hand, does your baby hold onto it for about 1 minute while looking at it, waving it about, or trying to chew it?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby grab or scratch his fingers on a surface in front of him, either while being held in a sitting position or when he is on his tummy?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you hold her in a sitting position, does your baby reach for a toy on a table close by even though her hand may not touch it?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Fine Motor Total

(Cut off 29.62)

Does your baby grab a toy you offer and look at it, wave it about, or chew on it for about 1 minute?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby reach for or grasp a toy using both hands at once?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby reach for a crumb and touch it with his finger? (If he already picks up a small object the size of a pea, check "yes" for this item.)

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby pick up a small toy, holding it in the center of her hands with her fingers around it?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby try to pick up a crumb by using his thumb and all his fingers in a raking motion, even if he isn't able to pick it up? (If he already picks up the crumb, check "yes" for this item.)

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby usually pick up a small toy with only one hand?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Fine Motor Total

(Cut off 27.5)

After one or two tries, does your baby pick up a piece of string with her first finger and thumb?

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby pick up a crumb with the tips of his thumb and a finger? He may rest his arm or hand on the table while doing it.

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby put a small toy down, without dropping it, and then take her hand off the toy?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Without resting his arm or hand on the table, does your baby pick up a crumb with the tip of his thumb and a finger?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your baby throw a small ball with a forward arm motion? (If he simply drops the ball, check "not yet" for this item.)

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your baby help turn the pages of a book? (You may lift a page for her to grasp.)

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Fine Motor Total

(cut off 28.4)

Does your child throw a small ball with a forward arm motion? (If he simply drops the ball, check "not yet" for this item.)

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child stack a small block or toy on top of another one? (You could also use spools of thread, small boxes, or toys that are about 1 inch in size.)

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child make a mark on the paper with the tip of a pencil or pen when trying to draw?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child stack three small blocks/boxes or toys on top of each other by herself?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child turn the pages of a book by himself?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child get a spoon into her mouth right side up so that the food usually doesn't spill?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Fine Motor Total

(Cut off 39.5)

Does your child get a spoon into her mouth right side up so that the food usually doesn't spill?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child turn the pages of a book by himself?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child use a turning motion with her hand while trying to turn doorknobs, wind up toys, twist bottle tops, or screw lids on and off jars?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child flip switches off and on?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child stack seven small blocks or toys on top of each other by himself?

☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child thread a shoelace through either a bead or an eyelet of a shoe?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Fine Motor Total

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)
 (Cut off 36.4)

Does your child use a turning motion with her hand while trying to turn doorknobs, windup toys, twist bottle tops, or screw lids on and off jars?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After he watches you draw a line from the top of the paper to the bottom with a pen or pencil, does your child make a line like yours?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child thread a shoelace through either a bead or eyelet of a shoe?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After she watches you draw a line from one side of the paper to the other side, does your child make a line like yours (without tracing your line)?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After he watches you draw a single circle, does your child make a circle like yours (without tracing your circle)?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child turn pages in a book, one page at a time?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Fine Motor Total

(Cut off 25.2)

If you draw a vertical line from the top of the paper to the bottom and ask your child to repeat it. Is your child able to draw a single line in a vertical direction?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child thread a shoelace through either a bead or an eyelet of a shoe?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After he watches you draw a single circle, is your child able to draw a circle like yours without tracing your circle?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After watching you draw a horizontal line from one side of the paper to the other, is your child able to draw a line without tracing your line?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child try to cut paper with scissors? Able to open and close the scissor normally?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When drawing, does your child hold a pencil or pen between her fingers and thumb like an adult does?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Fine Motor Total

(Cut off 30.7)

Problem Solving

When you move a toy slowly from side to side in front of his face (about 10 inches away), does your baby follow the toy with his eyes, sometimes turning his head?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you move a small toy up and down slowly in front of her face (about 10 inches away), does your baby follow the toy with her eyes?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you hold him in a sitting position, does your baby look at a toy (about the size of a cup or rattle) that you place on the table or floor in front of him?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you put a toy in her hand, does your baby look at it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you put a toy in his hand, does your baby put the toy in his mouth?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you dangle a toy above her while she is lying on her back, does your baby wave her arms toward the toy?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Problem Solving Total

(Cut off 34.98)

When a toy is in front of her, does your baby reach for it with both hands?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When he is on his back, does your baby turn his head to look for a toy when he drops it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When she is on her back, does your baby try to get a toy she has dropped if she can see it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby often pick up toys and put them in his mouth?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby pass a toy back and forth from one hand to the other?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby play by banging a toy up and down on the floor or table?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Problem Solving Total

(Cut off 37.0)

While holding a small toy in each hand, does your baby clap the toys together (like "Pat-a-cake")?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby poke at or try to get a crumb that is inside a clear bottle (such as plastic soda-pop bottle or baby bottle)?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After he watches you hide a small toy under a piece of paper or cloth, does your baby find it? (Be sure the toy is completely hidden.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

If you put a small toy into a bowl or box, does your baby copy you by putting in a toy, although she may not let go of it? (If she already let's go of the toy into a bowl or box, check "yes" for this item.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your baby drop two small toys, one after the other, into a container like bowl or box? (You may show him how to do it.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

After you scribble back and forth on paper with a crayon (or a pencil or pen), does your baby copy you by scribbling? *If she already scribbles on her own, check "yes" for this item.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Problem Solving Total

(Cut off 25.2)

Does your child drop several (six or more) small toys into a container, such as bowl or box? (You may show him how to do it.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

After you have shown her how, does your child try to get a small toy that is slightly out of reach by using a spoon, stick or similar tool?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

After a crumb is dropped into a small, clear bottle, does your child purposely turn the bottle over to dump it out? You may show him how to do this. You can use a baby bottle.

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Without first showing her how, does your child scribble back and forth when you give her a pencil or pen?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

After he watches you draw a line from the top of the paper to the bottom with a pen or pencil, does your child copy you by drawing a single line on the paper in any direction? (Scribbling back and forth does not count as "yes.")

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

After a crumb is dropped into a small, clear bottle, does your child turn the bottle upside down to dump out the crumb?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Problem Solving Total

(Cut off 33.0)

After she watches you draw a line from the top of a paper to the bottom with a pen or pencil, does your child copy you by drawing a single line on the paper in any direction?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Without showing him how, does your child purposefully turn a small, clear bottle upside down to dump out a crumb? (You can use a soda pop bottle)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child pretend objects are something else? For example, does your child hold a cup to her ear, pretending it is a telephone?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

Does your child put things away where they belong? For example, does he know his blanket goes on his bed?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Not yet (0)

If your child wants something she cannot reach, does she find a chair or box to stand on to reach it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child imitate you if you line up four objects in a row?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Problem Solving Total

(Cut off 32.9)

When looking in the mirror, and asking "Where is ____ (Your child's name)?" Does your child point to her image?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

If your child wants something he cannot reach, does he find a chair or box to stand on to reach it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

If you lined up 4 objects in a row. Does your copy or imitate you and line four objects in a row?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you point to a drawing and ask, "What is it?" Does your child give an appropriate response?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you say, "Say seven three" (or some other two numbers) Does your child repeat just the two numbers in the correct order?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After she draws a "picture," does your child tell you what she drew?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Problem Solving Total

(Cut off 28.9)

If you lined 4 objects in a row, is your child able to copy or imitate you and line up 4 objects?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

If your child wants something he cannot reach, does he find a chair or box to stand on to reach it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you point to a drawing and ask your child "What is this?" does your child say a word that is appropriate for describing the drawing?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you say, "Say seven three" (or any two numbers) does your child repeat just the two numbers in the correct order?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

If you showed your child how to make a bridge with blocks or boxes, would he be able to do it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you say, "Say five eight three" (or any three numbers) does your child repeat just the three numbers in the correct order?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Problem Solving Total

(Cut off 38.6)

Personal-Social

Does your baby watch his hands?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When she has her hands together, does your baby play with her fingers?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When he sees the breast or bottle, does your baby know he is about to be fed?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby help hold the bottle with both hands at once, or when nursing, does she hold the breast with her free hand?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Personal-Social Total

 (Cut off 33.16)

When in front of a large mirror, does your baby smile or coo at herself?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby act differently toward strangers than he does with you and other familiar people? (Reactions to strangers may include staring, frowning, withdrawing, or crying.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

While lying on her back, does your baby play by grabbing her foot?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When in front of a large mirror, does your baby reach out to pat the mirror?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

While on his back, does your baby put his foot in his mouth?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby try to get a toy that is out of reach? (She may roll, pivot on her tummy or crawl to get it.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Personal-Social Total

 (Cut off 27.5)

When you hold out your hand and ask for his toy, does your baby offers it to you even if he doesn't let go of it? (If he already let's go of the toy into your hand, check "yes" for this item.)

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you dress her, does your baby push her arm through a sleeve once her arm is started in the hole of the sleeve?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you hold out your hand and ask for his toy, does your baby let go of it into your hand?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When you dress her, does your baby lift her foot for her shoe, sock, or pant leg?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your baby play with a doll or stuffed animal by hugging it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Personal-Social Total

(Cut off 20.1)

While looking at himself in the mirror, does your child offer a toy to his own image?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child play with a doll or stuffed animal by hugging it?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child get your attention or try to show you something by pulling on your hand or clothes?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child come to you when she needs help, such as with winding up a toy or unscrewing a lid from a jar?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child drink from a cup or glass, putting it down again with little spilling?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child copy the activities you do, such as wipe up a spill, sweep, or comb hair?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Personal-Social Total

☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)
 (Cut off 37.0)

Does your child drink from a cup or glass, putting it down again with little spilling?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child copy activities you do, such as wipe up a spill, sweep, shave, or comb hair?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child eat with a fork?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When playing with either a stuffed animal or doll, does your child pretend to rock it, feed it, change its diapers, put it to bed, and so forth?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child push a little shopping cart, stroller, or wagon, steering it around objects and backing out of corners if he cannot turn?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child call herself "I" or "me" more often than her own name? For example, "I do it," more often than "Sarah do it."

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Personal-Social Total

(Cut off 35.6)

If you do any of the following gestures, does your child copy at least one of them? (a) open and close your mouth (b) blink your eyes (c) pull on your earlobe (d) pat your cheek.

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child use a spoon to feed himself with little spilling?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child push a little shopping cart, stroller, or wagon, steering it around objects and backing out of corners if she cannot turn?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child put on a coat, jacket, or shirt by himself?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

After you put on loose-fitting pants around her feet, does your child pull them completely up to her waist?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When he is looking in a mirror and you ask, "Who is in the mirror?" does your child say either "Me" or his own name?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Personal-Social Total

(Cut off 36.9)

Does your child use a spoon to feed herself with little spilling?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child push a little shopping cart, stroller, or wagon, steering it around objects and backing out of corners if he cannot turn?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

When she is looking in a mirror and you ask, "Who is in the mirror?" does your child say either "me" or her own name?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Can your child put on a coat, jacket, or shirt by himself?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Using these exact words, ask your child, "Are you a girl or a boy?" Does your child answer correctly?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Does your child take turns by waiting while another child or adult takes a turn?

- ☐ Yes (10)
☐ Sometimes (5)
☐ Notyet (0)

Personal-Social Total

(Cut off 38.7)

Maternal Information

Mother's First Name	_____
Mother's Middle Name	_____
Mother's Family Name	_____
Mother's date of birth	_____ (YYYY-MM-DD)
Is the mother currently living?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't know <input type="radio"/> Choose not to answer <input type="radio"/> Missing
Mother's current age	_____ (Years old)
How tall is the mother currently?	_____ (cm. "Don't know" = 999. "Choose not to answer" = 1000.)
How much does the mother currently weigh?	_____ (Kg. "Don't know" = 999. "Choose not to answer" = 1000.)
Mother's age at time of conception (when she became pregnant with this patient)	_____ (years. "Don't know" = 999. "Choose not to answer" = 1000.)
Are the Mother and Father of the patient related by blood in any way?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't know <input type="radio"/> Choose not to answer <input type="radio"/> Missing
Please describe their relationship (i.e. Mother and Father are first degree cousins)	<input type="radio"/> First degree cousins (son/daughter of aunt/uncle) <input type="radio"/> Second degree cousins (parents are first degree cousins) <input type="radio"/> More distant cousins (not first or second degree) <input type="radio"/> Other <input type="radio"/> Don't know <input type="radio"/> Choose not to answer <input type="radio"/> Missing
If other, please explain	_____

Maternal Obstetric/Gynecologic History

Number of Mother's prior live births	_____ ("Don't know" = 999. "Choose not to answer" = 1000.)
Number of Mother's prior still births (pregnancy lost at or greater than 24 weeks gestation)	_____ ("Don't know" = 999. "Choose not to answer" = 1000.)

Has the mother ever had an intentional (abortion) miscarriage?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate the number of intentional miscarriages

("Don't know" = 999. "Choose not to answer" = 1000.)

If yes, what was the method used to cause the abortion?

- ☐ Procedure in clinic
☐ Metal rod inserted into cervix
☐ Pill to terminate pregnancy
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain.

Has the mother ever had an accidental miscarriage?
(Pregnancy lost at less than 24 weeks gestation)

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate how many accidental miscarriages occurred and how many weeks pregnant the mother was during each miscarriage

How many full-term pregnancies has the mother had?
(Deliver at 37 weeks or more)

("Don't know" = 999. "Choose not to answer" = 1000.)

How many pre-term pregnancies has the mother had?
(Deliver at less than 37 weeks)

("Don't know" = 999. "Choose not to answer" = 1000.)

Has the mother ever had any periods of infertility?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate how long

(Months. "Don't know" = 999. "Choose not to answer" = 1000.)

Please provide the mother's age during the period of infertility

(years. "Don't know" = 999. "Choose not to answer" = 1000.)

Please describe any treatments the mother received for infertility

Maternal Past Medical History

Was the mother overweight/obese during pregnancy?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother have any medical problems prior to the pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all prior medical problems

- ☐ Diabetes Mellitus
☐ Tuberculosis
☐ Bleeding Disorder
☐ Heart problems
☐ Cancer
☐ Asthma
☐ Seizures
☐ High blood pressure
☐ Other
☐ Unknown
☐ Unanswered

If other, please explain

Did any of these problems require hospitalization?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother have any active medical problems during the time of delivery?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain

Maternal Immunization History

Was the mother immune to Rubella prior to pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the mother immune to Hepatitis A prior to pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the mother immune to Hepatitis B prior to pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother receive vaccinations during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please describe the vaccines received and how many weeks pregnant the mother was during vaccination

Prenatal Course

Did the Mother have any injuries during this pregnancy?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate mechanism of injury

- ☐ Vehicle-related accident
☐ Physical assault
☐ Traumatic fall
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Please indicate how many weeks pregnant the mother was during this injury

(weeks pregnant. "Don't know" = 999. "Choose not to answer" = 1000.)

Did any of these injuries require hospitalization?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How long did the mother remain hospitalized for due to this injury?

(Provide unit of time)

Did the mother have a seizure while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Missing
☐ Choose not to answer

If yes, how many weeks pregnant was she at the time of the seizure?

(Weeks pregnant. "Don't know" = 999. "Choose not to answer" = 1000.)

Did the mother have a respiratory infection while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Missing
☐ Choose not to answer

If yes, how many weeks pregnant was she at the time of the infection?

(Weeks pregnant. "Don't know" = 999. "Choose not to answer" = 1000.)

Did the mother have a bladder, kidney, urinary tract infection while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Missing
☐ Choose not to answer

If yes, how many weeks pregnant was she at the time of infection?

(Weeks pregnant. "Don't know" = 999. "Choose not to answer" = 1000.)

Did the mother undergo a surgery while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Missing
☐ Choose not to answer

If yes, how many weeks pregnant was she at the time of the surgery?

(Weeks pregnant. "Don't know" = 999. "Choose not to answer" = 1000.)

Did the mother receive an x-ray while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Missing
☐ Choose not to answer

If yes, how many weeks pregnant was she at the time of the x-ray?

(Weeks pregnant. "Don't know" = 999. "Choose not to answer" = 1000.)

Did the mother receive prenatal care during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Where did the mother receive prenatal care?

(Name of facility and city)

At how many weeks of her pregnancy did the mother receive this care?

(Weeks pregnant. "Don't know" = 999. "Choose not to answer" = 1000.)

From whom did the mother receive prenatal care?

- ☐ Medical Doctor
☐ Nurse
☐ Midwife
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Why did the mother not receive prenatal care?

- ☐ Travel constraints
☐ Financial constraints
☐ Did not feel a need to receive such care
☐ Did not know she was pregnant
☐ None of the above
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Did the mother take any medications during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please name the medicine, indicate the dose taken, and describe how many weeks pregnant the mother was during the time of taking it

Did the mother take folic acid supplements before becoming pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother take folic acid while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother take prenatal vitamins before becoming pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother take prenatal vitamins while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother take calcium supplements before becoming pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother take calcium supplements while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother take iron supplements before becoming pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother take iron supplements while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother take any other vitamins during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please name the vitamin(s) and describe how many weeks pregnant the mother was during the time of taking it

Did the mother take any herbs during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please name the herb(s) and describe how many weeks pregnant the mother was during the time of taking it

Was the mother exposed to any toxins during her pregnancy with this patient? (i.e., factory fumes)

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please name the toxin and describe how many weeks pregnant the mother was during the time of exposure

Did the mother smoke tobacco (including cigarettes, and argileh/hookah/water pipe) during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother smoke cigarettes during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How many cigarettes per day?

(Average number of cigarettes per day)

How many days per week?

How many weeks pregnant was the mother when she first smoked cigarettes?

(Weeks pregnant)

Did the mother smoke argileh (also known as hookah or water pipe) during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How many times per day did she smoke argileh?

(Average number of times smoked per day)

How many days per week did she smoke argileh?

How many weeks pregnant was the mother when she first smoked argileh?

(Weeks pregnant)

Please describe the form of tobacco smoked (including cigarettes, and argileh/hookah/water pipe) during pregnancy with this patient. How much tobacco was smoked daily, and list how many weeks pregnant the mother was during the time she was smoking

Was the mother living with someone who smoked during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Where did this person smoke?

- ☐ Inside of the house
☐ Outside of the house
☐ Both inside and outside of the house
☐ Don't know
☐ Choose not to answer
☐ Missing

How frequently was the mother exposed to tobacco smoke during her pregnancy with this patient?

- ☐ Daily
☐ Weekly
☐ Monthly
☐ Less than Monthly
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the mother exposed to any animals during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all animals the mother was exposed to

- ☐ Donkey
☐ Sheep
☐ Cat
☐ Goat
☐ Chickens
☐ Turkeys
☐ Ducks
☐ Horses
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Please describe the mother's access to food during her pregnancy with this patient

- ☐ Access food daily
☐ Access food 1-3 times a week
☐ Access food weekly
☐ Access food monthly
☐ Access food irregularly
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Was the mother eating three meals a day regularly while pregnant with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Were these meals nutritionally balanced (equal amounts of proteins/grains/vegetables/fruits)?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the mother eat meat during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What was the most common type of meat eaten by the Mother?

How was this meat cooked?

- ☐ Well-done
☐ Medium
☐ Rare
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

About how often did the mother eat meat?

- ☐ Everyday
☐ Once-a-week
☐ Once-a-month
☐ Never
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Did the mother eat fruits during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate about how often

- ☐ Everyday
☐ Once a week
☐ Once a month
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

What were the most common fruits eaten by the mother during her pregnancy with this patient?

Did the mother eat vegetables during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate about how often

- ☐ Everyday
☐ Once a week
☐ Once a month
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

What were the most common vegetables eaten by the mother during her pregnancy with this patient?

Did the mother have an ultrasound during her pregnancy with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the ultrasound show the cleft defect in the patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Prior to delivery of the patient, was the Mother aware that she was carrying a child with a cleft?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Who told the mother that her child had a cleft diagnosis?

- ☐ Nurse
- ☐ Medical Doctor
- ☐ Midwife
- ☐ No one
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

Once the patient was diagnosed with a cleft, was this diagnosis explained to the mother?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Did the mother understand what cleft lip/palate meant once her child received this diagnosis?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Did the mother receive information regarding this diagnosis from a healthcare provider?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Newborn Care

Did the Mother breast feed or bottle feed this patient during the first 6 months of life?

- ☐ Breast feed
- ☐ Bottle feed
- ☐ Both breast feed and bottle feed
- ☐ Other
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If other, please explain

How long did the mother exclusively breast feed?

(months)

Brief Maternal Family History

Do any genetic syndromes appear in the Mother's family?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please describe the syndrome(s)

Does thalassemia run in the mother's family?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

If yes, please select the type

- ☐ alpha-thalassemia
- ☐ beta-thalassemia
- ☐ both alpha- and beta-thalassemia
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Notes

Additional comments

Paternal Information

Father's First Name

Father's Middle Name

Father's Family Name

Father's date of birth

 (YYYY-MM-DD)

Is the Father currently living?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Father's current age

How much does the Father currently weigh?

(Kg. "Don't know" = 999. "Choose not to answer" = 1000.)

How tall is the father currently?

(cm. "Don't know" = 999. "Choose not to answer" = 1000.)

Father's age at the time that Mother became pregnant with this patient

(years old. "Don't know" = 999. "Choose not to answer" = 1000)

Paternal Past Medical History

Did the Father have any medical problems prior to the birth of this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all problems

- ☐ Diabetes Mellitus
☐ Tuberculosis
☐ Bleeding disorder
☐ Heart problem
☐ High blood pressure
☐ Cancer
☐ Asthma
☐ Seizures
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Please describe the cancer

Was the Father taking any medications during the time of conception (when Mother became pregnant) with this patient?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please describe the medication and dose

Brief Paternal Family History

Do any genetic syndromes appear in the Father's family?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please describe the syndrome(s)

Does thalassemia run in the father's family?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

If yes, please select the type

- ☐ alpha-thalassemia
☐ beta-thalassemia
☐ both alpha- and beta-thalassemia
☐ Don't know
☐ Choose not to answer
☐ Missing

Notes

Additional comments

Family Information

Family Cleft History

Are there any children with cleft lip/palate in this patient's immediate family?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How many other children?

("Don't know" = 999. "Choose not to answer" = 1000.)

What year(s) was this child or were these children born? (Separate each date of birth with a semicolon)

Please identify the type(s) of cleft lip/palate that best describes each child's diagnosis

- ☐ Complete cleft lip on left side
☐ Complete cleft lip on right side
☐ Incomplete cleft lip on left side
☐ Incomplete cleft lip on right side
☐ Complete alveolar cleft on left side
☐ Complete alveolar cleft on right side
☐ Incomplete alveolar cleft on left side
☐ Incomplete alveolar cleft on right side
☐ Complete hard palate cleft on left side
☐ Complete hard palate cleft on right side
☐ Incomplete hard palate cleft on left side
☐ Incomplete hard palate cleft on right side
☐ Complete soft palate cleft on left side
☐ Complete soft palate cleft on right side
☐ Incomplete soft palate cleft on left side
☐ Incomplete soft palate cleft on right side
☐ Don't know
☐ Choose not to answer
☐ Missing

Do any two children have the same cleft diagnosis?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate which cleft diagnoses are found in more than one child in the family

- ☐ Complete cleft lip on left side
- ☐ Complete cleft lip on right side
- ☐ Incomplete cleft lip on left side
- ☐ Incomplete cleft lip on right side
- ☐ Complete alveolar cleft on left side
- ☐ Complete alveolar cleft on right side
- ☐ Incomplete alveolar cleft on left side
- ☐ Incomplete alveolar cleft on right side
- ☐ Complete hard palate cleft on left side
- ☐ Complete hard palate cleft on right side
- ☐ Incomplete hard palate cleft on left side
- ☐ Incomplete hard palate cleft on right side
- ☐ Complete soft palate cleft on left side
- ☐ Complete soft palate cleft on right side
- ☐ Incomplete soft palate cleft on left side
- ☐ Incomplete soft palate on right side
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Do you have a relative with a cleft?

- ☐ Yes
 - ☐ No
- (This would be any blood relative with an orofacial cleft.)

How many relatives with cleft?
Multiplex Family
ID?

(Unique identifier for family groups with multiple clefts)

What is the relationship?

(Example: brother, maternal aunt, etc.)

Is the relative currently in the database?

- ☐ Yes
- ☐ No

What is the relative's registry number in the database?

What is the relative's phone number?

Is there another relative with cleft?

- ☐ Yes
- ☐ No

How many relatives with cleft?
Multiplex Family
ID?

(Unique identifier for family groups with multiple clefts)

What is the relationship?

(Example: brother, maternal aunt, etc.)

Is the relative currently in the database?

- ☐ Yes
- ☐ No

What is the relative's registry number in the database?

What is the relative's phone number?

Is there another relative with cleft?

- ☐ Yes
- ☐ No

How many relatives with cleft?

Multiplex Family
ID?

(Unique identifier for family groups with multiple
clefts)

What is the relationship?

(Example: brother, maternal aunt, etc.)

Is the relative currently in the database?

- ☐ Yes
☐ No

What is the relative's registry number in the
database?

What is the relative's phone number?

Family Congenital Anomaly History

Are there any children with developmental
abnormalities in the family (i.e. unable to speak,
unable to hear, growth delay)?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

If yes, please indicate the abnormality

- ☐ Unable to speak
☐ Unable to hear
☐ Growth delay
☐ Dwarfism
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Are there any children in this patient's immediate
family with other congenital anomalies?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all anomalies

- ☐ Cranial meningocele
☐ Microcephaly
☐ Encephalocele
☐ Neural tube defect
☐ Polydactyly
☐ Umbilical hernia
☐ Neurocutaneous syndrome
☐ Meningocele
☐ Agenesis of corpus callosum
☐ Amniotic band syndrome
☐ Hydrocephalus
☐ Club foot
☐ Imperforate anus
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Does anyone else in the patient's family have birth
defects?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was this a first degree (i.e., parent/child/sibling)
or second degree (i.e., aunt/uncle/cousin) relative?

- ☐ First degree relative
- ☐ Second degree relative
- ☐ More distant relative (than first and second degree)
- ☐ Don't know
- ☐ Choose not to answer
- ☐ Missing

Please describe the defect

Notes

Additional comments

General Information

Hearing

Has this patient undergone a hearing screening?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please provide the date of the initial hearing screening

(YYYY-MM-DD)

Was it determined that this patient had hearing loss?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What type of hearing loss?

- ☐ Central hearing loss
☐ Neural hearing loss
☐ Hearing loss due to infection
☐ Hearing loss due to scarring of eardrum
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Genetics

Has this patient seen a geneticist?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please provide the date that the patient saw a geneticist

(YYYY-MM-DD)

Please provide the name of the geneticist

Please provide the address of the geneticist

Was this a local or foreign geneticist?

- ☐ Local
☐ Foreign
☐ Don't know
☐ Choose not to answer
☐ Missing

Was your child diagnosed with a syndrome?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please provide the name or a description of the syndrome

Did the geneticist determine that the cleft was inherited?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Otolaryngology (Ears, Nose, Throat)

Has the patient seen an otolaryngologist (ear, nose, throat doctor)?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please provide the date that the patient saw the otolaryngologist

(YYYY-MM-DD)

Please provide the address of the otolaryngologist

Was this a local or foreign otolaryngologist?

- ☐ Local
☐ Foreign
☐ Don't know
☐ Choose not to answer
☐ Missing

Dental

Has the patient ever seen a dentist?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What date did the patient first see a dentist?

(YYYY-MM-DD)

Does the patient have dental problems?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Indicate all dental problems

- ☐ Cavities Extra
☐ teeth Crooked
☐ teeth Missing
☐ teeth
☐ Malformed/misshapen teeth
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Speech-Language Pathology

Has the patient seen a speech-language pathologist?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please provide the date that the patient saw a speech-language pathologist

(YYYY-MM-DD)

Please provide the name of the speech-language pathologist

Was this a local or foreign speech-language pathologist?

- ☐ Local
☐ Foreign
☐ Don't know
☐ Choose not to answer
☐ Missing

What agency did the speech-language pathologist work for?

Please provide the address of the speech-language pathologist

Was this visit for an evaluation or for therapy?

- ☐ Evaluation
☐ Therapy
☐ Don't know
☐ Choose not to answer
☐ Missing

Has the patient ever been seen for a speech evaluation?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What was the focus of the therapy?

- ☐ Articulation (clarity of speech)
☐ Language (understanding and use of concepts, vocabulary, and sentence structure)
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Is the patient's speech understandable?

- ☐ Yes
☐ No
☐ Too young to speak
☐ Don't know
☐ Choose not to answer
☐ Missing

Has the patient's speech ever become nasal after surgery?

- ☐ Yes
☐ No
☐ Non-applicable
☐ Don't know
☐ Choose not to answer
☐ Missing

Did it resolve?

☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

General

Has the patient had any antibiotics for ear infections?

☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How many times?

(“Don't know” = 999. “Choose not to answer” = 1000.)

Has the patient ever had ear tubes placed for ear infections?

☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What date?

(YYYY-MM-DD)

Has the patient ever seemed to stop breathing in the middle of the night?

☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Has the patient had excessive snoring?

☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Has the patient ever received a tracheostomy?

☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What date?

(YYYY-MM-DD)

Has the patient ever had his/her tonsils or adenoids removed?

☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

What date?

(YYYY-MM-DD)

Has this patient exhibited normal development since birth?

☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all areas of developmental delay

- ☐ Gross motor (i.e. walking, sitting up)
☐ Fine motor (i.e. using hands, holding pencil)
☐ Language (i.e. talking on time)
☐ Communication (i.e. appropriate eye contact)
☐ None of the above
☐ Don't know
☐ Choose not to answer
☐ Missing

Has the child developed any medical conditions since infancy?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain

Education

Is the patient in school?

- ☐ Yes
☐ No
☐ Completed school
☐ Dropped out of school
☐ Too young for school
☐ Don't know
☐ Choose not to answer
☐ Missing

What is the patient's grade level?

Is the patient performing at or above average for his/her grade level for his/her age?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Non-applicable
☐ Missing

Is the patient performing below average for his/her grade level for his/her age?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Non-applicable
☐ Missing

Indicate all areas of difficulty for this patient

- ☐ Reading
☐ Writing
☐ Arithmetic
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Has the patient ever been held back a grade level?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Non-applicable
☐ Missing

Has the patient ever had interruptions (breaks) in school?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was this due to external factors? (i.e. civil unrest, schools shut down, bad weather, family illness)

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please indicate all external factors

- ☐ Civil unrest
☐ Bad weather
☐ Schools shut down
☐ Family illness
☐ Travel barriers
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

If other, please explain

Notes

Additional comments

Cleft Repair Historical Information

Cleft Lip Repair

Has the patient undergone a primary cleft lip repair
(First cleft lip repair surgery) in the past?

- ☐ Yes
☐ No
☐ Non-applicable
☐ Don't know
☐ Choose not to answer
☐ Missing

When?

(YYYY-MM-DD)

Age at time of primary cleft lip repair

(months)

By whom?

Was this a foreign or local physician?

- ☐ Foreign
☐ Local
☐ Don't know
☐ Choose not to answer
☐ Missing

At what hospital?

Please provide the address of the facility where the
patient received this procedure

Was the patient able to feed better after this
procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the patient accepted better socially after this
procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did this procedure improve the patient's health?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did any complications occur with this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain

Cleft Palate Repair

Has the patient undergone a primary cleft palate repair (first palate repair surgery) in the past?

- ☐ Yes
☐ No
☐ Non-applicable
☐ Don't know
☐ Choose not to answer
☐ Missing

When?

(YYYY-MM-DD)

Age at time of primary cleft palate repair

(months)

By whom?

Was this a foreign or local physician?

- ☐ Foreign
☐ Local
☐ Don't know
☐ Choose not to answer
☐ Missing

At what hospital?

Please provide the address of the facility where the patient received this procedure:

Was the patient able to feed better after this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the patient accepted better socially after this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did this procedure improve the patient's health?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the patient's speech improved after surgery?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing
 (If patient is too young for speech, answer "Don't Know")

Did solid foods begin to leak out of the patient's nose when eating after receiving this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did liquids begin to leak out of the patient's nose eating or drinking after receiving this procedure?

- ☐ Yes when
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How frequently does this occur per day?

(Per day. "Don't know" = 999. "Choose not to answer" = 1000.)

Did any complications occur with this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain

Alveolar Bone Graft

Has the patient undergone an alveolar bone graft in the past?

- ☐ Yes
☐ No
☐ Non-applicable
☐ Don't know
☐ Choose not to answer
☐ Missing

When?

(YYYY-MM-DD)

By whom?

Was this a foreign or local physician?

- ☐ Foreign
☐ Local
☐ Don't know
☐ Choose not to answer
☐ Missing

At what hospital?

Please provide the address of the facility where the patient received this procedure

Was the patient able to feed better after this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the patient accepted better socially after this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did this procedure improve the patient's health?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the patient's speech improved after surgery?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did solid foods begin to leak out of the patient's nose when eating after receiving this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did liquids begin to leak out of the patient's nose eating or drinking after receiving this procedure?

- ☐ Yes when
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How frequently does this occur per day?

(Per day. "Don't know" = 999. "Choose not to answer" = 1000.)

Did any complications occur with this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain

Jaw (orthognathic) Surgery

Has the patient undergone a jaw (orthognathic) surgery in the past?

- ☐ Yes
☐ No
☐ Non-applicable
☐ Don't know
☐ Choose not to answer
☐ Missing

When?

(YYYY-MM-DD)

By whom?

Was this a foreign or local physician?

- ☐ Foreign
☐ Local
☐ Don't know
☐ Choose not to answer
☐ Missing

At what hospital?

Please provide the address of the facility where the patient received this procedure

Was the patient able to feed better after this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the patient accepted better socially after this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did this procedure improve the patient's health?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the patient's speech become nasal after the surgery?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did the patient's speech become clearer after the surgery?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did any complications occur with this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain

Revision of Lip/Nose

Has the patient undergone a revision of lip/nose in the past?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

When?

(YYYY-MM-DD)

By whom?

Was this a foreign or local physician?

- ☐ Local
☐ Foreign
☐ Don't know
☐ Choose not to answer
☐ Missing

At what hospital?

Please provide the address of the facility where the patient received this procedure

Was the patient able to feed better after this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the patient accepted better socially after this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did this procedure improve the patient's health?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Was the patient's speech improved after surgery?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did solid foods begin to leak out of the patient's nose when eating after receiving this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Did liquids begin to leak out of the patient's nose eating or drinking after receiving this procedure?

- ☐ Yes when
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

How frequently does this occur per day?

(Per day. "Don't know" = 999. "Choose not to answer" = 1000.)

Did any complications occur with this procedure?

- ☐ Yes
☐ No
☐ Don't know
☐ Choose not to answer
☐ Missing

Please explain

Other

In total, how many operations has the patient undergone to correct the cleft?

(“Don't know” = 999. “Choose not to answer” = 1000.)

Has the patient received other surgical procedures not discussed above?

- ☐ Yes
☐ No
☐ Other
☐ Don't know
☐ Choose not to answer
☐ Missing

Please name and date all other procedures and indicate if the surgeon was local or foreign

On average, approximately how much has the patient's healthcare cost annually?

(Shekels. “Don't know” = 999. “Choose not to answer” = 1000.)

In total, throughout the patient's lifetime, approximately how much has the patient's healthcare cost?

(shekels. “Don't know” = 999. “Choose not to answer” = 1000.)

Notes

Please expand upon any of the surgeries mentioned above, including when they were performed, by whom, and if any complications occurred. If this is a follow-up visit, please list any surgeries the patient has undergone since their last visit.

Additional comments

Intervention Information

Did the patient receive an operation as a result of this screening visit?

☐ Yes
☐ No

Hospital where intervention took place

(Use formal hospital name)

Vitals

Blood Pressure

(Not measured = 999)

Heart Rate

(beats per minute). Not measured = 999)

Pre-operative patient information

Does the patient have allergies?

☐ Yes
☐ No
☐ Don't Know

List patient's medication allergies

List patient's other allergies

List patient's other health problems

Name of evaluator

Title of evaluator

☐ Clerk
☐ Surgeon
☐ Nurse
☐ Other

Date of evaluation

(YYYY-MM-DD)

Surgical Treatment

Date of admission

(YYYY-MM-DD)

Date of surgical treatment

(YYYY-MM-DD)

Date of discharge

(YYYY-MM-DD)

Name of surgeon

Name of anesthesiologist

Anesthesia method

☐ General
☐ Local

Type of operation

- ☐ Primary Lip/Nose Unilateral Repair (partial or complete)
☐ Primary Lip/Nose Bilateral Repair (partial or complete)
☐ Primary Cleft Palate Repair
☐ Fistula Repair
☐ Secondary Cleft Palate (Velopharyngeal) Repair
☐ Lip/Nose Revision
☐ Alveolar Bone Graft
☐ Other

If other, please explain

Type of repairs

- ☐ Unilateral Lip
☐ Bilateral Lip
☐ Palate

Indicate specific type of repair method used for a Unilateral Lip

- ☐ Rotation-Advancement Variant
☐ Triangular Variant
☐ Others

Indicate specific type of repair method used for a Bilateral Lip

- ☐ Straight line
☐ Forked flap
☐ Others

Indicate specific type of repair method used for a Palate

- ☐ Langenbeck variant
☐ Pushback variant
☐ Others

Were there any complications, injury, or patient mortality?

- ☐ Yes
☐ No

Did these complications result in patient death or serious physical or psychological injury to the patient?

- ☐ Yes
☐ No

Please indicate type of complication

- ☐ Blood transfusion
☐ Breathing problems
☐ Dehiscence
☐ Delayed oral feeding
☐ Fistula
☐ Return to OR

Notes

Additional Comments on Intervention

Photos

Pre Surgery

Frontal

Worms-Eye View / Inferior / Nasal Base

Cleft Side Lateral

Intra-Oral

Additional Photo(s)

Post-Surgery

Frontal

Worms-Eye View / Inferior / Nasal Base

Cleft Side Lateral Intra-

Oral Frontal/Smiling

Additional Post Photo(s)

Notes

Additional comments

Appendix B

CCHMC_Adult_Consent_Form-5_AR

IRB #: 2015-0607



Approved:
7/26/2016
Do Not Use After:
5/25/2017

<p style="text-align: right;">عنوان الدراسة: قاعدة بيانات حول التشوهات الخلقية في دولة فلسطين</p> <p style="text-align: right;">رقم الدراسة: 0607-2015</p> <p style="text-align: right;">المنظمة الممولة: Middle East Craniofacial Care Institute (مؤسسة الرعاية القحفية الوجهية بالشرق الأوسط)</p> <p style="text-align: right;">John A. van Aalst (جون أ. فان أالست) اسم الباحث الرئيسي</p> <p style="text-align: right;">Hassan Zawahrah (حسن زواهره)، منسق الدراسة 0597271078 رقم الهاتف</p>
<p style="text-align: right;">مقدمة</p> <p>ندعوك للمشاركة في دراسة بحثية حتى تتمكن من التوصل إلى معلومات جديدة قد تساعد الآخرين. إذا قررت عدم المشاركة في هذه الدراسة، سنظل نقدم لك الرعاية الجيدة. إذا قررت المشاركة في هذه الدراسة، قد نخبر رأيك في أي وقت خلال الدراسة ويمكنك التوقف عن المشاركة فيها. لا تتعجل في اتخاذ قرارك. واطرح علينا أي سؤال يدور في ذهنك. ولا بأس من طرح المزيد من الأسئلة بعد اتخاذ قرارك بشأن المشاركة في الدراسة. ويمكنك طرح الأسئلة في أي وقت.</p> <p style="text-align: right;">لماذا نجري هذا البحث؟</p> <p>في هذه الدراسة البحثية نود معرفة معلومات أكثر عن التشوهات الخلقية بين الفلسطينيين، خاصة تلك المتعلقة بفلج الشفة والحنك. ونحن نطلب من طفلك ومن الأطفال الآخرين المصابين بفلج الشفة والحنك (وكذلك التشوهات القحفية الوجهية الخلقية الأخرى) أن يشاركوا في البحث لأننا نرغب في معرفة المزيد من المعلومات حول كيفية حدوث تلك التشوهات وكيفية تحسين رعاية الأطفال المصابين بها.</p> <p style="text-align: right;">من المسؤول عن هذا البحث؟</p> <p>يُجري هذه الدراسة د. جون أ. فان أالست، الباحث في مركز مستشفى سينسيناتي للأطفال الطبي (Cincinnati Children's Hospital Medical Center). وكذلك السيد حسن الزواهره، منسق البحث بدولة فلسطين، والذي يقيم بيت لحم ويساعد في تنسيق جهودنا البحثية.</p> <p>لا يتقاضى مركز مستشفى سينسيناتي للأطفال الطبي أي مقابل مادي نظير إجراء هذه الدراسة.</p>
<p style="text-align: right;">من الأشخاص الذين لا يستطيعون المشاركة في الدراسة؟</p> <p>لا يمكنك للمشاركة في هذه الدراسة إذا لم تكن مصابًا بعيب خلقي ولادى مثل فلج الشفة والحنك، صغر صيوان الأذن، ورم وعائي، وحمية خلقية، تشوه وعائي، وفرط التباعد، أو بعض الحالات الأخرى المماثلة.</p>

<p>ما الذي سيحدث في الدراسة؟</p> <p>سيقوم فريق البحث بشرح إجراءات كل زيارة لك، وقد يمنحك نشرة تشرح كل زيارة بمزيد من التفاصيل. وستتمكن من طرح الأسئلة لضمان استيعابك لكل ما سيحدث.</p> <p>إذا كنت مؤهلاً وقررت المشاركة في الدراسة، فسيطرح عليك عدة أسئلة في صورة استبيان. هذا الاستبيان سوف يستغرق ساعة واحدة لإكماله. سيتم وضع جميع الأجوبة على الاستبيان في قاعدة بيانات على الإنترنت محمية بكلمة مرور، تسمى REDCaps.</p> <p>وفيما يلي عرض للأشياء التي سوف تحدث لك أثناء مشاركتك في الدراسة: في أول زيارة مع مساعدي البحث لدينا، سوف يطرح عليك أسئلة من الاستبيان الذي قمنا بوضعه.</p> <p>وفي زيارات المتابعة كل عام، سوف نطرح عليك أسئلة محددة أكثر بكثير حول حالتك الصحية، سواء خضعت لأية عمليات جراحية، من عدمه.</p> <p>وستقوم كذلك بالتقاط الصور لك في كل زيارة. سيتم تحميل هذه الصور إلى قاعدة بيانات REDCaps.</p>	<p>ما هي الأمور الجيدة التي يمكن أن تحدث نتيجة المشاركة في هذا البحث؟</p> <p>قد لا نستفيد من المشاركة في هذه الدراسة في الوقت الحالي. إننا نأمل، عند الانتهاء من هذه الدراسة، في معرفة المزيد حول مدى شوع التشوهات الخلوية بين الفلسطينيين. ففي المستقبل، سيساعدنا ذلك على اتخاذ القرارات حول كيفية تحسين الرعاية لجميع الفلسطينيين المصابين بتلك المشكلات الخلوية.</p> <p>ما هي الأمور السيئة التي يمكن أن تحدث نتيجة المشاركة في هذا البحث؟</p> <p>وحيث إن الدراسة مقتصرة على أسئلة الاستبيان، وكذلك أسئلة المتابعة، عندما نراك مرة أخرى، لذا فإن المشكلة الوحيدة التي قد تطرأ هي فقدان السرية. ومن أجل حماية السرية الخاصة بك، لن يتم الاحتفاظ بنسخ ورقية من إجاباتك. وجميع المعلومات من الاستبيان والصور سيتم تحميلها مباشرة إلى قاعدة البيانات المؤمنة على الإنترنت.</p>
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<p>قد يُطرح عليك أسئلة قد تجعلك تشعر بقلق أو تذكر مواقف كانت مزعجة بالنسبة لك. لست مضطراً للإجابة على أية أسئلة لا ترغب في إجابتها ويمكنك التوقف عن استكمال الاستبيان في أي وقت. وإذا ما شعرت بالزعاج شديد أثناء الاستبيان في أي وقت كان، فستقوم بإنهاء الاختبار. وسنتيح لك كذلك الحديث مع شخص ما حول ما تشعر به.</p>
<p>ما هي الخيارات الأخرى المتاحة؟</p> <p>بدلاً من مشاركتك في هذه الدراسة يمكنك اختيار عدم المشاركة فيها.</p>
<p>كيف سيتم الاحتفاظ بالمعلومات الخاصة بك بشكل سري؟</p> <p>إن التأكد من أن المعلومات الخاصة بك تظل سرية هو أمر هام بالنسبة لنا. لحماية خصوصيتك في هذه الدراسة البحثية، فلن يتم الإبقاء على أي نسخ ورقية من الإجابات التي تقدمها، وسيتم إدخال إجابات الأسئلة على الفور في قاعدة البيانات على الإنترنت.</p>
<p>ماذا يحدث إذا توافرت لدينا معلومات جديدة أثناء إجراء البحث؟</p> <p>سيخبرك الطبيب المسؤول عن الدراسة في حالة التوصل لمعلومات جديدة ناتجة عن هذه الدراسة أو الدراسات الأخرى والتي قد تؤثر على صحتك أو سلامتك أو رغبتك في البقاء في هذه الدراسة.</p>
<p>هل سيكلفك ذلك أي نفقات إضافية نظير المشاركة في هذه الدراسة البحثية؟</p> <p>لن تفرض عليك أية رسوم نظير المشاركة في هذه الدراسة.</p>
<p>هل سيتم الدفع لك مقابل الاشتراك في هذه الدراسة البحثية؟</p> <p>لن يتم الدفع لك مقابل الاشتراك في هذه الدراسة البحثية.</p>
<p>ماذا يحدث إذا تعرضت للإصابة نتيجة المشاركة في هذه الدراسة؟</p> <p>لأن هذه الدراسة المعلوماتية تتضمن فقط طرح أسئلة من الاستبيان والتقاط صور، فلن تتعرض لأي إصابة في هذه الدراسة.</p>

<p>ما هي الجهة التي ستتصل بها إذا كان لديك أسئلة أو واجهت مشكلات؟</p> <p>لن طرح الأسئلة أو الاستفسار عن المشكلات أو الإبلاغ عن الشكاوى المتعلقة بهذه الدراسة البحثية يمكنك الاتصال بالشخص المسؤول عن الدراسة الوارد ذكره في الصفحة 1 من هذه الوثيقة.</p> <p>إذا كنت ترغب في التحدث إلى أحد الأشخاص الذي لا ينتمي للفريق البحثي أو إذا كان لديك أسئلة عامة بشأن حقوقك الخاصة بالدراسة البحثية أو استفسارات أو مخاوف أو شكاوى تتعلق بالبحث يمكنك الاتصال على مجلس المراجعة المؤسسي (Institutional Review Board) في مركز مستشفى سينسيناتي للأطفال الطبي على الرقم 513-636-8039. يمكنك كذلك الاتصال بالسيد حسن زواهره على رقم الموبيل المحلي: 0597271078.</p>
<p>ما الذي يجب أن تعرفه أيضًا عن هذا البحث؟</p> <p>إننا نقدر لك مشاركتك في هذه الدراسة.</p>
<p>تصريح باستخدام المعلومات الصحية للأغراض البحثية أو الإفصاح عنها</p> <p>لكي تشارك في هذه الدراسة البحثية يجب عليك أيضًا السماح (أو التصريح) باستخدام "المعلومات الصحية المحمية" (التي تسمى اختصارًا <i>PHI</i>) والإفصاح عنها (أو تبادلها).</p> <p>ما هي المعلومات الصحية المحمية التي سيتم استخدامها وتبادلها أثناء هذه الدراسة؟</p> <p>سيحتاج مركز مستشفى سينسيناتي للأطفال الطبي إلى استخدام وتبادل المعلومات الصحية المحمية الخاصة بك كجزء من هذه الدراسة. ومصدر هذه المعلومات الصحية المحمية من إجابتك على أسئلة الاستبيان.</p> <p>من الذي سيتبادل المعلومات الصحية المحمية الخاصة بك في هذه الدراسة أو يحصل عليها أو يستخدمها؟</p> <ul style="list-style-type: none"> الموظفون في جميع مواقع الدراسة البحثية (بما في ذلك مركز مستشفى سينسيناتي للأطفال الطبي) الموظفون الذين يقدمون الخدمات لك بوصفك جزءاً من هذه الدراسة أفراد آخرون أو منظمات تحتاج إلى استخدام معلوماتك الصحية المحمية المتعلقة بالبحث، بما في ذلك الأشخاص لدى الجهة المشرفة على الدراسة والمنظمات التي قد تستخدمها الجهة المشرفة للإشراف على الدراسة أو إجرائها. أعضاء مجلس المراجعة المؤسسي بمركز مستشفى سينسيناتي للأطفال الطبي (وموظفو المكتب المعني بالبحوث والشؤون التنظيمية (Office of Research Compliance and Regulatory Affairs). <p>كيف ستعرف أن معلوماتك الصحية المحمية لا يساء استخدامها؟</p> <p>يخضع الأشخاص الذين يحصلون على معلوماتك الصحية المحمية بوصفك جزءاً من هذا البحث بشكل عام لقيود فيما يتعلق بكيف يمكنهم استخدام هذه المعلومات. وبالإضافة إلى ذلك فإن معظم الأشخاص الذين يحصلون على معلوماتك الصحية المحمية هم أيضًا مطالبون بحمايتهم بموجب قوانين الخصوصية الفيدرالية. ومع ذلك، فإن بعض الأشخاص الذين يحصلون على معلوماتك الصحية المحمية قد لا يُطلب منهم حمايتهم ويجوز لهم مشاركة المعلومات مع آخرين دون إذن منك، إذا سمحت بذلك القوانين المطبقة عليهم.</p> <p>هل يمكنك تغيير رأيك؟</p> <p>يمكنك اتخاذ قرار سحب موافقتك في أي وقت. ومن شأن سحب موافقتك على استخدام معلوماتك الصحية المحمية ومشاركتها أن يشمل أيضًا الانسحاب من المشاركة في الدراسة البحثية. وإذا كنت ترغب في سحب موافقتك على استخدام معلوماتك الصحية المحمية ومشاركتها فستحتاج إلى إخطار طبيب الدراسة، المذكور في الصفحة الأولى من هذه الوثيقة، كتابيًا. وسيكون طلبك ساريًا على الفور ولن يتم استخدام المعلومات الصحية المحمية الخاصة بك أو مشاركتها من جديد. والاستثناءات من ذلك فقط هي (1) أي استخدام أو مشاركة للمعلومات الصحية المحمية التي تمت بالفعل أو كانت تحدث قبل سحب موافقتك و(2) أي استخدام أو مشاركة تعد ضرورية للحفاظ على سلامة البحث.</p> <p>هل ينتهي العمل بهذا التصريح؟</p> <p>سينتهي العمل بهذا التصريح في نهاية هذه الدراسة. وتتضمن الدراسة إنشاء مستودع قاعدة بيانات بحثية والاحتفاظ به ولن ينتهي العمل بالتصريح الخاص به.</p>

<p>هل ستتأثر الرعاية الطبية الأخرى الخاصة بك؟</p> <p>من خلال التوقيع على هذه الوثيقة فإنك توافق على المشاركة في هذه الدراسة البحثية وتمنح موافقتك لمركز مستشفى سينسيناتي للأطفال الطبي لاستخدام المعلومات الصحية المحمية الخاصة بك ومشاركتها لأغراض هذه الدراسة البحثية. في حالة رفضك التوقيع على هذه الوثيقة لن تتمكن من المشاركة في الدراسة. ولكن لن تتأثر حقوقك المتعلقة بالعلاج التي لا علاقة لها بهذه الدراسة، أو عملية الدفع مقابل الخدمات، أو التسجيل في خطة سداد نفقات الرعاية الصحية، أو التأهيل من أجل الاستفادة.</p>	
<p>التوقيعات</p> <p>لقد ناقش الفريق البحثي هذه الدراسة معك وأجاب عن جميع أسئلتك. وكما هو الحال في أي أبحاث أخرى، لا يستطيع الباحثون التنبؤ بما يمكن أن يحدث على وجه الدقة. وبمجرد حصولك على الوقت الكافي للتفكير في ما إذا كنت ستشارك في هذا البحث أم لا فسوف توقي موافقتك بالتوقيع أدناه.</p> <p>سوف تحصل على نسخة من هذه الوثيقة الموقعة للاحتفاظ بها في سجلاتك.</p> <p>اسم المشارك في البحث بأحرف الطباعة</p> <p>توقيع المشارك في الدراسة البحثية بما يشير إلى الموافقة</p> <p>التاريخ</p> <p>توقيع الشخص المفوض قانونًا المفوض*</p> <p>التاريخ</p> <p>* إذا وقع الممثل القانوني المفوض على هذا النموذج، فيجب تقديم شهادة التفويض</p> <p>توقيع الشخص الذي حصل على الموافقة</p> <p>التاريخ</p>	

Appendix C

IRB approval

An-Najah
National University
Faculty of medicine Sciences &
Health
Institutional Review Board



جامعة النجاح
الوطنية
كلية الطب وعلوم الصحة
لجنة أخلاقيات البحث
العلمي

Ref: Mas Nov. 2020/31

IRB Approval Letter

Study Title:

"Maternal and paternal risk factors associated with Palestinian cleft patients"

Submitted by:

Muath Hasan Tayyem

Supervisor:

Abdulsalam Khayyat

Date Approved:

30th Nov. 2020

Your Study Title "Maternal and paternal risk factors associated with Palestinian cleft patients" viewed by An-Najah National University IRB committee and was approved on 30th Nov. 2020

Hasan Fitian, MD

IRB Committee Chairman

An-Najah National University



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جامعة النجاح الوطنية

كلية الدراسات العليا

عوامل الخطورة للأمومة والأبوة المرتبطة بمرضى الشفة الارنبية وسقف الحلق المفتوح

إعداد

معاذ تيم

إشراف

د. عبد السلام الخياط

قدمت هذه الأطروحة استكمالاً لمتطلبات الحصول على درجة الماجستير في الصحة العامة، بكلية الدراسات العليا، في جامعة النجاح الوطنية، نابلس - فلسطين.

2022

عوامل الخطورة للأمومة والأبوة المرتبطة بمرضى الشفة الأرنبية وسقف

الحلق المفتوح

إعداد

معاذ تيم

إشراف

د. عبد السلام الخياط

الملخص

المقدمة: تعتبر الشفة الأرنبية وسقف الحلق المشقوق من أكثر تشوهات الوجه الخلقية شيوعاً عند الأطفال حديثي الولادة وتختلف الإصابة بناءً على العرق ومسببات الإصابة. وهي مرتبطة بالعديد من عوامل الخطورة بما فيها العوامل البيئية والجينية والجغرافية. يمكن أن يساعد تحديد عوامل الخطر في الوقاية من الإصابة وتقليل معدلها. لذا تهدف هذه الدراسة الى تحديد عوامل الخطر المرتبطة بالإصابة بالشفة الأرنبية وسقف الحلق المشقوق في المجتمع الفلسطيني.

الطريقة: هذه الدراسة عبارة عن دراسة استيعادية وصفية وغير عشوائية، وذلك باستخدام استبانة تم إجراؤها مع أولياء أمور الأطفال الفلسطينيين المصابين بالتشوهات الخلقية في مستشفيات الضفة الغربية.

النتائج: احتوت الدراسة على 543 مريضاً مصاباً بالشفة الأرنبية او سقف الحلق المشقوق او كلاهما، وكان أعلى معدل للإصابة متركز في المناطق الجنوبية للضفة الغربية، مع عدم وجود ارتباط كبير بين الوضع الريفي أو الحضري أو اللجوء. (53%) من الآباء والأمهات كانوا أقارب. فقط 13% من المرضى لديهم على الأقل شخص واحد مصاب بتشوهات في الوجه (الشفة الأرنبية أو سقف الحلق المشقوق او كلاهما) بقرابة دم من الدرجة الأولى، و43% منهم كان لديهم أقارب

من الدرجة الثانية أو أبعد. 95% من أمهات المرضى تلقين رعاية ما قبل الولادة و14% فقط من الأجنة تم الكشف عن اصابتهم بتشوه في الوجه (الشفة الأرنبية أو سقف الحلق المشقوق أو كلاهما) في صورة الموجات فوق الصوتية، فقط 5% من الأمهات تناولن حمض الفوليك قبل الحمل و60% منهم تناولن حمض الفوليك خلال الحمل. كان معدل التدخين لأمهات الأطفال الذين يعانون من الشفة الأرنبية أو سقف الحلق المشقوق أو كلاهما هو 4%، ولكن 64% تعرضن للتدخين السلبي.

الخلاصة: تبين أن زواج الأقارب وتعرض الأم للتدخين وقلة تناول حمض الفوليك قبل وأثناء الحمل هي عوامل خطر تزيد احتمالية إنجاب أطفال بتشوهات خلقية (الشفة الأرنبية وسقف الحلق المشقوق). وتبين أنه لا يوجد ترابط واضح بين الجنس أو الحالة المدنية بزيادة خطر الإصابة بالشفة الأرنبية وسقف الحلق المشقوق. يوجد حاجة للمزيد من الدراسات والابحاث، ويجب أن تؤخذ بعين الاعتبار البرامج التعليمية.

الكلمات المفتاحية: تشوهات الفم والوجه، الشفة الأرنبية وسقف الحلق المشقوق، عوامل الخطر، فلسطين.