The Virtual Center for Velo-Cardio-Facial Syndrome and Related Craniofacial Disorders History Form for Craniofacial Disorders and/or Syndromes

INSTRUCTIONS: This PDF document is a fillable form. If you have Adobe Reader or Adobe Acrobat (Standard or Pro) on your computer, you will be able to fill out this form. If you do not have Adobe Reader or Acrobat on your computer, you can download Reader from the internet free of charge. Simply search "Adobe Reader" using your preferred search engine (Google, Yahoo, etc.) and download and install Adobe Reader on your computer. Adobe Reader is free of charge. The form consists of some fill-in questions, many questions that can be answered with a click on a check box or circle, and some pull-down menus. After you have filled in the form, save it and email it to us at info@vcfscenter.com. If you are having problems filling out the form, let us know by email and we will send you a form you can fill out with a pen or pencil. Hand filled forms can be sent to by fax at 1-480-247-4290 or you can mail it to us at: Virtual Center for VCFS, 8138 Solomon Seal Lane, Manlius, NY 13104.

IMPORTANT: BEFORE FILLING OUT ANYTHING ELSE BELOW, IT IS IMPORTANT FOR US TO KNOW HOW WE MAY BEST HELP YOU. THEREFORE, PLEASE LIST THE PROBLEMS YOU ARE MOST CONCERNED ABOUT OR ASK THE QUESTIONS YOU WANT ANSWERED IN THE SPACES PROVIDED BELOW THIS PARAGRAPH AND THE SPACE FOR THE NAME OF THE PERSON WITH A CRANIOFACIAL OR CLEFT DISORDER. YOU MAY LIST UP TO 6 PROBLEMS OR QUESTIONS, BUT IF YOU NEED MORE, SIMPLY ADD ON TO THE LIST AT THE END OF THE FORM WHERE THERE WILL BE A SPACE PROVIDED. PLEASE NOTE: QUESTIONS HIGHLIGHTED IN RED ARE MANDATORY AND REQUIRE A RESPONSE.

NAME OF PERSON WITH CRANIOFACIAL DISORDER

1.**PLEASE LIST THE PROBLEMS YOU ARE CONCERNED ABOUT**

2.

3.

4.

5.

6.

Name of registrant to web site:

Primary telephone number of registrant (include country code if outside of U.S.):

Mobile phone or other contact number:

Email address:

Fax number:

MAILING ADDRESS

Name of person with a craniofacial disorder

Sex of person with a craniofacial disorder:

Date of birth of person with a craniofacial disorder:

What is the craniofacial disorder (name, or description):

When was this problem detected (what age)?

Parent's name and date of birth (mother):

Parent's name and date of birth (father)

How did you hear about the Virtual Center?

Do you or have attended a specialty clinic or center?

- yes
- no

If yes, the name or place of the specialty clinic/center

HISTORY: PLEASE FILL OUT THE FORM AS ACCURATELY AS POSSIBLE. Check the items that apply

Pregnancy: were there any problems?

- yes
- no

Problems (please check all that apply)

- Bleeding or spotting
- Polyhydramnios
- Preeclampsia
- Reduced fetal movement
- Other

If you checked "other," please describe the problem(s)

Was pregnancy full term (40 weeks)?

- Yes
- No

If pregnancy was not full term, how many weeks was it?

How many ultrasound examinations did you have during pregnancy?

Was anything abnormal found?

Did you have amniocentesis?

- Yes
- No

What was the result if you had amniocentesis?

Delivery

	Spontaneous vaginal delivery	Emergency C-section	Planned C-section
Delivery			

Reason for Caesarean section (C-section)

Birth weight

Length at birth

Head circumference

Apgar scores

Length of hospital stay

Describe problems at delivery, if any

Siblings, please list age or birth dates and sex, names are optional

Does anyone else in the family have the same or a similar problem?

- Yes
- No
- Uncertain

If yes, please describe relationship (mother, father, brother, sister, etc.) and age, If uncertain, please describe.

Problems present at and shortly after birth

Check all of the problems listed below that were present at or shortly after birth

- Low muscle tone
- Nasal regurgitation
- Difficulty breathing
- Cyanosis
- Difficulty eating/nursing
- Other

If you checked "other," please describe the problem

If there was difficulty eating/nursing, please describe the problem

Feeding Problems

Check all of the problems that apply

- Difficulty feeding
- Reflux
- Chronic vomiting
- Chronic constipation
- Refusal of solid foods
- Preference for soft foods
- Limited diet
- Other

If you checked "other," please describe the problem

Why was feeding difficult?

How was reflux diagnosed? Was a pH probe done?

Is constipation still present? How often do bowel movements occur (number per week)

What foods are preferred and what foods are rejected?

Has esophagoscopy ever been done?

- Yes
- No

If yes, what was found?

Ears

Is there a history of frequent ear infections?

- Yes
- If yes, are they still occurring
- No

If yes, at what age did they start and at what age did they stop?

Is there hearing loss?

- Yes, right ear only
- Yes, left ear only
- Yes, both ears
- No

If yes, what type of hearing loss?

- Conductive
- Sensori-neural
- Mixed (both conductive and sensori-neural)

Hearing loss severity (pull down menu)

Describe the cause of the hearing loss

Throat

Were tonsils removed?

- Yes
- No
- Unknown

If yes, why were they removed? Was there total removal or intracapsular tonsillectomy?

Were adenoids removed? If yes, why were they removed?

- Yes
- No
- Unknown

Sleep

Are there any sleep problems? If yes, please describe the problem.

- Yes
- No
- Unknown

Growth

Any problems with growth? What is current height and weight (please indicate units of measurement)

- Yes
- No
- Unknown

Eyes

Are there any eye or vision problems? If yes, please describe.

- Yes
- No
- Unknown

Neurology

Has your child ever had a seizure? If yes, at what age was the first seizure? How many seizures have occurred? (pull down menu)

- Yes
- No
- Unknown

Have seizures continued to the current time?

- Yes
- No

If medication is taken for seizures, what is the medication?

Has an EEG ever been done? If yes, what was found?

- Yes
- No
- Unknown

Has a brain MRI or CT scan ever been done? If yes, what was found?

- Yes
- No
- Unknown

Check any of the following that apply: If you checked "other problems," please describe the problem

- Low muscle tone (hypotonia)
- Excessive muscle tone (hypertonia)
- Movement disorder (severe impairment of normal movements)
- Other problems

Development, Cognition, and Motor Milestones

Were early motor milestones delayed?

- Yes
- No
- Not sure

Age when first independent steps were taken (age of walking)

Age when first word was produced

Are there any cognitive or intellectual problems, including learning disabilities? If you checked "yes," please describe the problem

- Yes
- No
- Unknown

Speech and Language

Check all of the following that apply:

- Speech delay
- Hypernasality
- Hyponasality
- Language impairment
- Articulation impairment
- Apraxia/dyspraxia
- Hoarseness
- Unintelligible speech

If speech therapy is being administered, how often is it provided, and describe the best way you can what is being done.

If speech therapy is currently being administered, and you are a parent or guardian, do you sit in on the sessions?

- Yes
- No

If speech therapy is currently being administered, and you are a parent or guardian, are you given specific assignments at home?

- Yes
- No

If yes, what are you asked to do?

If hypernasality or hyponasality have been diagnosed, what procedures have been done for assessment? Check all that apply.

- Listening to speech
- Nasopharngoscopy
- Videofluoroscopy
- Nasometry
- Other

If you checked "other," please name the procedure

Psychology/Psychiatry

Do you have any concerns about behavior?

- Yes
- No

If yes, please describe your concerns in as much detail as possible.

Has a complete neuropsychological assessment been done? This would consist of a variety of tests of intelligence, perception, learning skills, and behavior.

- Yes
- No
- Unknown

If yes, what was found?

Other health problems

- Congenital heart disease
- Kidney problems
- Spine problems
- Limb/hand/feet problems
- Adominal problems
- Breathing problems
- Other

If you checked "other," please describe the problem

Describe any of the other medical problems in as much detail as possible

Education/Learning/Cognition

If in school, what grade in school is the person with the craniofacial problem attending?

Are any special services provided in school?

- Yes
- No

If yes, please list any special accommodations that have been made

Are any special educational services being received outside of school?

- Yes
- No

If yes, what are the special services received outside of school?

LIST CURRENT MEDICATIONS BEING TAKEN

LIST ANY SURGICAL PROCEDURES RECEIVED, AND THE DATES (OR APPROXIMATE DATES) WHEN THEY WERE PERFORMED

IS THERE ANYTHING ELSE YOU THINK WE SHOULD KNOW? IF YES, PLEASE LIST THESE THINGS IN DETAIL BELOW

IMPORTANT: PLEASE LET US KNOW YOUR PREFERRED METHOD FOR AN APPOINTMENT WITH US (SEE OUR WEB SITE FOR ADDITIONAL INFORMATION). WE PREFER VIDEO CALLS, BUT TELEPHONE APPOINTMENTS ARE ALSO POSSIBLE.

Preferred method for an appointment

- Video conference call
- Telephone conference call