The Virtual Center for VCFS

The Virtual Center for Velo-Cardio-Facial Syndrome History Form for Velo-Cardio-Facial Syndrome

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 HERE IN THE SPACES PROVIDED IMMEDIATELY BELOW THIS PARAGRAPH AND THE SPACE WHERE YOU WILL ENTER THE NAME OF THE PERSON WITH VCFS. 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 velo-cardio-facial syndrome (VCFS)

1. LIST THE PROBLEMS YOU ARE MOST 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 VCFS:

Sex of person with VCFS:

Date of birth of person with VCFS:

Date of VCFS diagnosis (approximate if actual date not known):

How was diagnosis made?

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 for VCFS?

- 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 (check those that apply)

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

If other, please described

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 VCFS?

- ○ Yes
- ○ No
- ○ Uncertain

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

Were parents tested for VCFS?

- ○ Yes
- ○ No

If tested, what were the results?

Problems present at and shortly after birth

Check all of the problems listed below that were present at 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

Heart and Vascular Problems

Check all of the anomalies that were found

- ☐ Ventricular septal defect
- ☐ Atrial septal defect
- ☐ Tetralogy of Fallot
- ☐ Truncus arteriosus
- ☐ Coarctation of the aorta
- ☐ Double aortic arch
- ☐ Interrupted aortic arch, type B
- ☐ Right sided aortic arch
- ☐ Anomalous subclavian artery
- ☐ Other

If you checked "other," please describe the problem

If you marked other, please list what was found

Gastrointestinal System

Check all of the problems that apply

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

If you checked "other," please describe the problem

Describe why feeding was difficult.

If present, how was reflux diagnosed? Was a pH probe done?

If present, 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
- Unknown

If yes, what was found?

Kidneys

Has a renal ultrasound ever been done and what was found if done?

- Yes
- No
- Unknown

If ultrasound was done, what was found?

- Normal
- Absent kidney
- Small kidney on one side
- Small kidneys on both sides
- Horseshoe kidney(s)
- Cystic kidney(s)
- Hydronephrosis
- Other

If you checked "other," what was found?

Immunology and Infectious Disease

Check all problems that have occurred or are occurring

- Frequent upper respiratory infections
- Pneumonia
- Bronchitis
- Thrush
- Sepsis
- Myocarditis (heart infection)
- Urinary tract infection
- Fungal infections
- Other infections

If you checked "other infections," please describe them

If pneumonia or bronchitis have occurred, how many times has it happened and at what ages?

Has a bronchoscopy ever been done?

- Yes
- No
- Unknown

If yes, what was found?

Has an immunologic evaluation been done?

- Yes
- No
- Unknown

If yes, what were the results?

Are immunizations up to date?

- Yes
- No
- Unknown

If no, what immunizations were withheld

Check if your child has had one or both of these shots

- Prevnar
- Pneumovax
- Unknown

Ears

Is there a history of frequent ear infections?

- Yes
- No
- Unknown

If yes, are they still occurring, and if not, 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?

- Yes
- No
- Partial adenoidectomy
- Unknown

If yes, why were they removed?

Sleep

Are there any sleep problems?

- Yes
- No
- Unknown

If yes, please describe the problem.

Endocrinology

Any problems with growth?

- Yes
- No
- Unknown

What is current height and weight (please indicate units of measurement)

Has there ever been a problem with calcium levels?

- Yes
- No
- Unknown

If yes, are calcium levels still a problem?

- Yes
- No

If yes, at what age where abnormal calcium levels first detected?

Is there a history of thyroid problems?

- Yes
- No
- Unknown

If yes, what is the problem?

Has there ever been a history of hypoparathyroidism?

- Yes
- No
- Unknown

If yes, has hypoparathyroidism persisted?

- Yes
- No
- Unknown

If there are other endocrine problems, please described.

Eyes

Are there any eye or vision problems?

- Yes
- No
- Unknown

If yes, please describe.

Neurology

Has your child ever had a seizure?

- Yes
- No
- Unknown

If yes, at what age was the first seizure?

How many seizures have occurred? (pull down menu)

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?

- Yes
- No
- Unknown

If yes, what was found?

Has a brain MRI or CT scan ever been done?

- Yes
- No
- Unknown

If yes, what was found?

Skeletal/Orthopedic/Muscles

Is there a history of leg pains?

- ○ Yes
- ○ No
- ○ Unknown

Is there a history of scoliosis?

- ○ Yes
- ○ No
- ○ Unknown

Is there a history of any other skeletal issues?

- ○ Yes
- ○ No
- ○ Unknown

If yes, please describe

Check any of the following that apply:

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

If you checked "other muscle problems," please describe the problem

Development 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

Speech and Language

Check all of the following that apply:

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

If you checked "hypernasality," please check all of the diagnostic tests shown below that have been done to assess the problem

- ☐ Listening to it
- ☐ Nasopharyngoscopy
- ☐ Videofluoroscopy
- ☐ Nasometry
- ☐ Other

If you checked "other," what was the test?

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 of someone with VCFS, do you sit in on the sessions?

- ○ Yes
- ○ No

If speech therapy is currently being administered, and you are a parent of someone with VCFS, are you given specific assignments at home?

- ○ Yes
- ○ No

If yes, what are you asked to do?

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?

Do you know the IQ of the person with VCFS?

- ○ Yes
- ○ No

If you know the IQ score, what is it?

At what age was this IQ score obtained?

Was more than one IQ score obtained?

- ○ Yes
- ○ No
- ○ Unknown

If yes, please list all scores and the ages obtained.

Education/Learning/Cognition

If in school, what grade in school is the person with VCFS 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