

# Participant Information Survey

We want to welcome you to our study and thank you for joining our study of Craniosynostosis, through your registration on our website: <https://genetics.ucdmc.ucdavis.edu>.

In order to study the environmental factors that may possibly cause craniosynostosis, we ask that you please complete the survey below. This online survey is divided into several sections and you can save your progress within each section. All responses to the survey will be kept confidential and shared only with the craniosynostosis collaborators (researchers) that are in the International Craniosynostosis Consortium (<https://genetics.ucdmc.ucdavis.edu/icc.cfm>).

You will also receive an email from us to coordinate sending you sample collection kits, for our study (Mouthwash and/or cheek swab).

Please don't hesitate to contact us with any questions by either by email ([hs-boydlab@ucdavis.edu](mailto:hs-boydlab@ucdavis.edu)) or by calling 916-703-0454.

Participant's First Name \_\_\_\_\_

Participant's Middle Name \_\_\_\_\_

Participant's Last Name \_\_\_\_\_

Date of Birth \_\_\_\_\_

Gender  Female  Male

Diagnosis (Pick all that apply)

- Sagittal
- Metopic
- Right Coronal
- Left Coronal
- Bicoronal
- Right Lambdoidal
- Left Lambdoidal

Participant's Race: (check all that apply)

- Caucasian
- African American
- Asian
- American Indian
- Other

Other \_\_\_\_\_

Are you Hispanic?  Yes  No

Street Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_

Zip Code \_\_\_\_\_

Primary Phone Number \_\_\_\_\_

Fax Number \_\_\_\_\_  
E-mail \_\_\_\_\_

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**Mother's Information**

Mother's First Name \_\_\_\_\_

Mother's Middle Name \_\_\_\_\_

Mother's Last Name \_\_\_\_\_

Mother's Date of Birth \_\_\_\_\_

Mother's Age at Conception \_\_\_\_\_

Mother's Race: (check all that apply)

- Caucasian
- African American
- Asian
- American Indian
- Other

Other \_\_\_\_\_

Mother's Ethnicity: Are you Hispanic?  Yes  No

Mother's Street Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_

Zip Code \_\_\_\_\_

Primary Phone Number \_\_\_\_\_

Work Phone \_\_\_\_\_

Cell Phone \_\_\_\_\_

Fax Number \_\_\_\_\_

Email \_\_\_\_\_

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**Father's Information**

Father's First Name \_\_\_\_\_

Father's Middle Name \_\_\_\_\_

Father's Last Name \_\_\_\_\_

Date of Birth \_\_\_\_\_

Age at Conception \_\_\_\_\_

Father's Race (Check all that apply)

- Caucasian
- African American
- Asian
- American Indian
- Hispanic
- Other

Other \_\_\_\_\_

Father's Ethnicity: Are you Hispanic?  Yes  No

Father's Street Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_

Zip Code \_\_\_\_\_

Primary Telephone \_\_\_\_\_

Work Telephone \_\_\_\_\_

Cell Phone \_\_\_\_\_

Fax Number \_\_\_\_\_

Email Address \_\_\_\_\_

**Siblings**

Does the participant have brothers or sisters (siblings)?  Yes  No  Don't Know

Sibling 1

Name \_\_\_\_\_

Gender  Female  Male

Date of Birth \_\_\_\_\_

Full Sibling?  Yes  No

Paternal Half Sibling?  Yes  No

Maternal Half Sibling?  Yes  No

Sibling 2

Name \_\_\_\_\_

Gender  Female  Male

Date of Birth \_\_\_\_\_

Full Sibling?  Yes  No

Paternal Half Sibling?  Yes  No

Maternal Half Sibling?  Yes  No

Sibling 3

Name \_\_\_\_\_

Gender  Female  Male

Date of Birth \_\_\_\_\_

Full Sibling?  Yes  NoPaternal Half Sibling?  Yes  NoMaternal Half Sibling?  Yes  No**Participant History**

Where was the participant born? \_\_\_\_\_

Participant's Birth Weight \_\_\_\_\_

(Numbers only &amp; 2 decimal places)

Participant's Birth Weight  lbs  kg

Birth Length \_\_\_\_\_

(Numbers only &amp; 2 decimal places)

Birth Length  in  cm

Head Circumference \_\_\_\_\_

Head Circumference  in  cm

Apgar Score \_\_\_\_\_

(1min/5min)

Was the baby full-term?  Yes  No  Don't Know

Born at how many weeks? \_\_\_\_\_

When was the mother's last period before the participant's birth? \_\_\_\_\_

How was the participant delivered?

- Vaginally, normal  
 Vaginally, with forceps  
 Vaginally, with vacuum extraction  
 Vaginally, with a breech position  
 C-section, due to size  
 C-section, due to a breech position  
 Other

Other, please explain: \_\_\_\_\_

Are you aware of any placental or umbilical cord defects?  No  Yes  Don't Know

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**Right after birth did the participant suffer from any of the following? If yes, please explain.**

10a) Jaundice requiring treatment?

 No    Yes    Don't Know

Explain

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10b) Trouble with oxygenation (cyanosis)

 No    Yes    Don't Know

Explain

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10c) Blood sugar problems

 No    Yes    Don't Know

Explain

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10d) Breathing difficulty and/or suction required

 No    Yes    Don't Know

Explain

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10e) Other (describe):

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**General Health History**

11a) What is the participant's current age (years and months):

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11b) What is the participant's current height

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11b) What is the participant's current height

 in    cm

11c) What is the participant's current weight

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11c) What is the participant's current weight unit

 lbs    kg

12) Participant's Diagnosis

- 
- sagittal
- 
- 
- unicoronal left
- 
- 
- unicoronal right
- 
- 
- metopic
- 
- 
- unilambdoid left
- 
- 
- unilambdoid right
- 
- 
- multiple sutures
- 
- 
- Other

Please Explain

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Is participant syndromic?

 No    Yes    Don't Know

13) At what age was the diagnosis made? Please indicate the age in years and months (yy/mm):

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- 14) Did the participant have a head CT?  No  Yes  Don't Know
- a) Age at diagnosis (age in years and months - yy mm) \_\_\_\_\_
- b) Result \_\_\_\_\_
- c) When and Where was the CT done? \_\_\_\_\_
- d) Can you mail us a copy of the CT scan results?  Yes  No
- 15) Did the participant have other imaging studies (MRI etc.)?  No  Yes  Don't Know
- Please explain \_\_\_\_\_
- 16) Does the participant have other congenital anomalies?  No  Yes  Don't Know
- Please explain \_\_\_\_\_
- 17) Has the participant ever had a clinical genetics evaluation?  No  Yes  Don't Know
- a) Where \_\_\_\_\_
- b) When \_\_\_\_\_
- c) By whom (Contact Info) \_\_\_\_\_
- 18) Has the participant ever had a chromosome analysis?  No  Yes  Don't Know
- a) Where \_\_\_\_\_
- b) When \_\_\_\_\_
- c) Results \_\_\_\_\_
- 19) Has the participant ever had surgery?  No  Yes  Don't Know
- 20) Has the participant had a history of hearing problems?  No  Yes  Don't Know
- 21) Has the participant had a history of vision problems?  No  Yes  Don't Know
- 22) Has the participant had a history of headaches?  No  Yes  Don't Know
- 23) Has the participant had a history of seizures?  No  Yes  Don't Know
- 24) Has the participant had a history of torticollis?  No  Yes  Don't Know

**25) Has the participant ever had problems with any of the following:**

- 25a) Skin Problems  No  Yes  Don't Know
- 25b) Face/Skull  No  Yes  Don't Know
- 25c) Brain  No  Yes  Don't Know
- 25d) Eye  No  Yes  Don't Know
- 25e) Heart  No  Yes  Don't Know
- 25f) Lung  No  Yes  Don't Know
- 25g) Kidney  No  Yes  Don't Know
- 25h) Intestinal  No  Yes  Don't Know
- 25i) Joints  No  Yes  Don't Know
- 25j) Limb  No  Yes  Don't Know
- 25k) Skeletal/Spinal  No  Yes  Don't Know
- 25l) Other  No  Yes  Don't Know
- 25l) Other Problems Explain \_\_\_\_\_

**26) Does the participant have any of the following developmental delays?**

- 26a) Motor  No  Yes  Don't Know
- 26b) Speech  No  Yes  Don't Know
- 26c) Learning  No  Yes  Don't Know
- 26d) Behavioral  No  Yes  Don't Know

**27) Please indicate when the participant was able to:**

- 27a) Sit without being propped (years/months) \_\_\_\_\_
- 27b) Stand without holding on to anything (years/months) \_\_\_\_\_
- 27c) Speak 10 words(years/months) \_\_\_\_\_
- 27d) Speak in short sentences (years/months) \_\_\_\_\_
- 27e) Additional Information or Comments: \_\_\_\_\_

28) If the participant is school age, is he or she in an age appropriate grade level?

No  Yes  Don't Know

If no, please explain.

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29) Is the participant or has the participant been in special education programs?

No  Yes  Don't Know

If Yes, please explain.

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30) If there is any additional information that you feel is relevant or may be helpful to the study, please enter here:

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